

**2012 UPDATED CHAPTER I:
BALANCING THE PRESENTATION OF INFORMATION AND OPTIONS
(Original Title: “Balancing The Presentation Of Options”)**

**SECTION 1:
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NOTE

The original title for this dimension (“Balancing The Presentation of Options”) is too narrow in scope. The original title is limited to the balance in type and number of “options” presented (i.e., which and how many options), and does not extend to the balance of information presented within each option. Given that the literature highlights the importance of complete, balanced, and unbiased presentation of all available options as well as information about all aspects of those options, we feel that the chapter title should be changed to “Balancing The Presentation of Information and Options”).

The original dimension chapter is included here as an Appendix.

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SECTION 2: CHAPTER SUMMARY

What is this dimension?

The extent to which a decision aid is “balanced” is the extent to which it presents—in content, in format, and in display—the available options and the positive and negative information about each of those options in a complete and neutral manner. The intention is to enable individuals to understand the options and their relevant information without influencing those individuals towards favouring or rejecting any particular option.

What is the theoretical rationale for including this dimension?

The basic purpose of a patients’ decision aid is to foster informed decision making by improving the understanding of risk and benefits of all treatment options, improving the comprehension of probability information about their condition and its treatment, creating more realistic expectations about the consequences of options, and improving clarity about personal values. In order to achieve these goals, information must be presented in a complete and neutral manner.

If information is incomplete, people may inadvertently overvalue or devalue a treatment option. If information is presented in a non-neutral manner, that can stimulate in individuals cognitive biases that can unduly affect people’s knowledge, their perceptions of risks and benefits, and, ultimately, their preferences. These untoward effects would, in turn, undermine the achievement of the decision aid’s purpose. At the same time, there is considerable debate about whether or not decision aids ethically ought to “nudge” patients towards options for which there is clear strong evidence for beneficial outcomes.

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

A literature search for articles published since 1980 identified 878 papers; among these, 38 reported on the “balance” of patient decision aids. Three more papers were identified in the 2009 Cochrane Collaboration’s Systematic Review of randomized controlled trials of patient decision aids. Among the resultant total of 41 eligible papers, only 10 studies had more than 10 respondents.

Among these 10 studies, we identified which papers explicitly reported that the balance of the relevant decision aids was assessed, then, in each of those papers, we determined how that assessment was carried out. In all cases, the balance of the decision aid was exclusively assessed from the users’ or patients’ perspective. While studies tended to use a 5-point Likert-type scale, we found inconsistency in the response formats used.

Finally, we focused on the extent to which the assessment of balance had been affected by using, in the relevant decision aids, side-by-side tables to compare and contrast the available options. Our analysis suggests that the inclusion of a summary table of any kind in which the options are compared was associated with more subjects (ranging from 70% to 96%) judging the information as “balanced” in its presentation.

We conclude by highlighting the need to a) develop a consensus on the definition of “balance” and on the methods used to assess balance, and b) carry out a range of comparative studies investigating different ways to improve the balanced presentation of information, as well as different ways to capture respondents’ assessments of the extent to which a decision aid is balanced or not.

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

Description of Literature Review

For this Section 3 and for Section 4, a literature search was performed using the following terms: *balanced presentation of information*, *unbiased presentation of information*, *non-directive presentation of information*, and *neutrality*. A total of 41 papers were selected for inclusion in this review (see Section 5 for further details about the selection process). We examined the selected papers from two perspectives: 1) whether and how the concept of “balance” was defined; and 2) what rationale was provided for “balancing the information and options” within decision aids. Of the 41 articles, only 12 defined this quality dimension, explicitly or implicitly and explained the rationale for including the dimension as a criterion for assessing the quality of DAs. The remaining articles provided no conceptual or theoretical details; they were mere descriptions of the development and/or testing of DAs, simply providing findings regarding the perceived balance of information among users.

We extracted the following information from the subset of articles: the terms used for the quality dimension; how the quality dimension was defined; and the rationale for including the quality dimension. A summary of the literature review can be found in Table 1.

a) Updated Definition

“Balance” refers to complete, unbiased and neutral presentation of the relevant options and the information about those options—in content, in format, and in display—in a way that enables individuals to process this information without bias.

The new definition emerged from the literature review, and reflects the following points.

- Balance refers to a) the content of the information (i.e., what information is presented, such as risks, benefits, procedures), b) the format of presentation (e.g., framing, absolute vs. relative, words vs. numbers), as well as c) the display of information (e.g., graphic vs. text) (Wills 2003).
- Balance occurs when information is complete (i.e., all relevant information is provided). Thus, all available options, which may include an option “to do nothing”, are presented, and information on all aspects of treatment—including risks, benefits, and treatment procedures—is presented (Feldman-Stewart 2007, Griffith, 2008).
- Balance occurs when there is equal emphasis on presenting positive and negative information (Feldman-Stewart 2007, Evans 2007, Zikmund-Fisher 2008).
- Balance is achieved when information is unbiased; the information is presented in a non-directive manner, without attempting to influence the uptake (or rejection) of any option (Martin 2011, Roberts 2004).

- Balance occurs when information is presented in a neutral manner, i.e., in a way that minimises cognitive biases (such as order effects, framing effects, primacy-recency bias, or denominator bias), avoids placing a value judgement on the information, and places equal weight on equally important information (Ubel 2010).
- Balance refers to the presentation of information in a way that enables individuals to process this information without bias (Winterbottom, 2008).

b) Changes to the Definition

The original chapter did not provide an explicit definition of this quality dimension. However, there was an implication that information presented in a balanced manner is that which does not inadvertently persuade the user to accept or reject a particular option.

The new definition has the following characteristics:

- It includes the attribute “complete” – which refers to the presentation of all the relevant options (which may include the option of “doing nothing”) and the presentation of information on all aspects of those options (i.e., risks, benefits, uncertainties, procedures, consequences).
- It includes the attribute “unbiased” – which refers to presentation in a way that does not deliberately or inadvertently influence the uptake or rejection of a particular option.
- It includes the attribute “neutral” – which refers to presentation in a way that places equal weight on positive and negative information and avoids placing a value judgement on the information.
- It highlights that “balance” applies to the content of information (i.e., what information is presented) as well as the format and display of information (i.e., how it is presented and displayed).
- It refers to the impact of presentation on individuals’ information processing (i.e., their gaining of knowledge, their formulation of risk & benefit perceptions, and their construction of preferences).

c) Emerging Issues with Definitions

- Challenges to this new definition arise from the large amount of data emerging from the decision sciences and behavioural economics that demonstrate how difficult it is to avoid influencing decisions in one direction or another, given a) the large number of biases that are induced by how information is framed and b) the fact that information must be framed one way or another.
- The new definition includes a provision that the presentation of the “do nothing” option may be necessary for a balanced decision aid. Whether the presentation of the “do nothing” option

is necessary for a balanced decision aid is currently under debate. We recognize that for some health-related decisions, it would seem odd to offer the “do nothing” option, such as cases in which the expert community’s opinion is to treat in one way or another, or in which the patient wants a particular treatment. Thus, this could be conceptualized as “the patient must be given information about the consequences of doing nothing.” Giving information about the consequences of doing nothing is what is ethically important as outlined by The American Medical Association’s statement on Informed Consent (<http://www.ama-assn.org/ama/pub/physician-resources/legal-topics/patient-physician-relationship-topics/informed-consent.page>).

SECTION 4: THEORETICAL RATIONALE FOR INCLUDING THIS QUALITY DIMENSIONS

a) Original Theoretical Rationale

The goal of an autonomous decision also implies that the presentation of information should not favour a specific option (Hope, 1996). There is empirical evidence that variations in the presentation of information affects how health is perceived, and how therapeutic choices are made and acted upon (Herrin, 2001; Jorgensen & Gotzsche, 2004). For example, depending on the framing of the data (e.g., using mortality or survival rates), patients make different treatment choices (Bohmer & Sepucha, 2003). Furthermore, the way in which information is presented influences patients’ satisfaction, knowledge, understanding, participation in decision-making, continuance of chosen options, coping with their situation, and search for further information (Christensen-Szalanski et al., 1987; Broyles et al., 1992; Inglis & Farnill, 1993; Phatouros & Blake, 1995; Michie et al., 1999).

Unbalanced information can create therapeutic expectations that are unrealistic, and can lead patients to unwittingly undertake interventions that carry chances of harms that they might not willingly accept. Since it is not only dishonest but also unethical to create unrealistic expectations or to obscure the chances of harm (Raffle 1997; 1999; 2001), patient decision aids must aim to present information in a balanced manner that does not inadvertently persuade the user to accept or reject a particular option.

b) Updated Theoretical Rationale

The theoretical rationale for this dimension remains largely unchanged from the original rationale. Of the 41 papers included in this review, a rationale for balancing the presentation of information and options was provided in only 6 of the 12 included papers, none of which referred to any specific theory or framework (see Table 1). (See also Table 2, for outlines of relevant methodological comments provided by these papers.) However, most explain the rationale in terms of the psychological processes that are affected by the cues in the context of the decision information.

A summary of the relevant theoretical points is given here.

- To enable informed decision making, information must be unbiased and must provide a balanced view (Roberts 2004).
- The basic purposes of providing information in decision aids are to create more realistic expectations about the consequences of options, to improve understanding of risk and benefits of options, to improve understanding of probabilistic information, and to improve clarity about personal values. In order to achieve these goals, information must be presented in a balanced manner and without bias (Zikmund-Fisher 2008).
- Some aspects of comprehension may be influenced by information-processing tendencies that are naturally associated with the structures and functions of our central nervous system. When information is not complete and balanced, people may ignore missing but relevant information, devalue a treatment option partially or completely, or make inferences about unavailable information based on the information that they do have (i.e., people may engage in biased information processing) (Feldman-Stewart, 2007).
- The manner in which information about options is presented influences people's perceptions of those options. Some formats of information presentation introduce cognitive biases (e.g., order, framing, primacy, or recency effects). Cognitive biases refer to heuristic strategies used by individuals that may lead to judgements that depart from accepted norms of rationality. These cognitive biases can unduly affect people's knowledge, perceptions of risks and benefits, and preferences. Presenting information in an unbalanced manner creates opportunities for cognitive biases, and risks placing a value judgement on the information that is inconsistent with the goal of neutrality (Ubel, 2010).
- Certain types of information (e.g., patient "narratives"; see Chapter E, "Using Personal Stories") may encourage the use of heuristic processing. Processing information heuristically relies on the use of "rules of thumb" based on an individual's past experiences and observations. In such circumstances, the context of the message, such as who is delivering the information, is more influential in decision making than the message content, such as information about the risks and benefits of treatment options. When patient narratives are presented, individuals may well be persuaded by others' stories because of a characteristic of the narrator rather than the content of the message (Winterbottom 2008).

The information extracted from the reviewed papers was synthesised in the light of the information processing paradigm to provide the updated theoretical rationale.

The basic purpose of a patients' decision aid is to foster informed decision making, by improving the understanding of risk and benefits of options, improving the comprehension of probability information, creating more realistic expectations about the consequences of options, and improving clarity about personal values. An informed decision is made when individuals take into account the consequences of all the available options, b) assess the likelihood and value of those consequences without bias, and c) make trade-offs between these evaluations (Janis and Mann, 1977, Bekker et al. 1999). This requires significant cognitive resources and effort. As human beings, we have finite cognitive resources for acquiring, storing, processing and

retrieving decision-related information (Payne & Bettman, 2004). As a result, we employ two types of strategy to process information (Chaiken, 1980):

- Heuristic processing (system 1) – involves unconscious ‘rules of thumb’ often triggered by the cues in the environment/context of the decision information, requires little cognitive effort, and is less time-consuming.
- Systematic processing (system 2) – involves analytical strategies, requires considerable conscious effort and is time-consuming.

For decisions that involve some degree of uncertainty or difficult trade-offs, individuals have a natural preference for the heuristic strategies as they minimise the load on their cognitive resources. This means that they are more likely to be influenced by the subtle cues in the context of the information (i.e., how information is presented) rather than the content of the information (such as risks and benefits of options) (Baron, 2000, Payne & Bettman, 2004). If information is incomplete, people may inadvertently overvalue or devalue a treatment option. If information is presented in a non-neutral manner, that can stimulate a range of cognitive biases that can unduly affect people’s knowledge, their perceptions of risks and benefits, and, ultimately, their preferences. These untoward effects would, in turn, undermine the achievement of the decision aid’s purpose. For this reason, it is important that decision aids present all the relevant options and information about those options in a complete, unbiased and neutral manner – in content, format and display.

**Table 1. Definitions and Theories About Balancing the Presentation of Options and Information in Patients' Decision Aids:
A Summary of Relevant Empirical Papers**

Author, Year	Terms Used To Describe The Quality Dimension How do the authors refer to this quality dimension? E.g., balanced presentation; unbiased presentation; any other reference?	Definition of 'Balance' How do the authors define 'balance'?	Theory a. Which theoretical framework is described? b. What rationale is provided for balancing the presentation of options?
(Elwyn, O'Connor et al. 2006)	DAs are unbiased	N/A	N/A
(Elwyn, O'Connor et al. 2009)	N/A ¹	N/A	N/A
(Evans, Elwyn et al. 2007)	Balance of the information	N/A	N/A
(Feldman-Stewart, Brennenstuhl et al. 2007)	Accuracy Balance/Imbalance	The information must be relevant, accurate, updated and complete.	N/A
(Griffith, Fichter et al. 2008)	Clarity and balance	Subjective measurement of DAs which avoids inclination to one decision.	N/A
(Martin, Brower et al. 2011)	Importance of unbiased (accurate) recall of information.	Accurate recall of information.	N/A
(Roberts, Raynes-Greenow et al. 2004)	DAs use information that is unbiased. DAs are non-directive in the sense that they do not aim to influence the uptake of either option.	No influence on the uptake of either option.	Rationale: To assist in informed decision making, information must be unbiased and based on current high quality evidence. Must give a balanced view and not ignore uncertainties and scientific controversies.

<p>(Ubel, Smith et al. 2010)</p>	<p>Neutrality</p>	<p>-Absence of cognitive biases (e.g., order effects such as recency and primacy bias, denominator bias). -Goal of DA developers: to inform patients about alternatives in a neutral manner. -Judgment about whether risk or benefit information is more important would be a value judgment that departs from neutrality. -Aim should be to place equal weight on equally important information.</p>	<p>Rationale: Cognitive biases (i.e., order effects of recency and primacy biases) negatively affect knowledge comprehension. Participants who did not receive “bias-eliminating” contextual information and received tamoxifen risk information last and benefit information first had higher knowledge scores than those who received risk information first, but no such order effect was seen among participants who received “bias-eliminating” risk context information. Order effects also affected how worried they were about the side effects of tamoxifen, and how impressed they were with tamoxifen’s ability to prevent breast cancer; no such order effect was seen among participants who received risk context information.</p> <p>Rationale: Neutrality avoids value judgments.</p>
<p>(Wills and Holmes-Rovner 2003)</p>	<p>Complete and balanced treatment-related information</p>	<p>Not explicitly defined</p>	<p>Rationale: The goal of providing relevant, complete and balanced information is to: create more realistic expectations about choice consequences, improve understanding of probability information, and improve clarity about personal values.</p> <p>What happens when information is not complete and balanced: people may ignore missing information, devalue a treatment option partially or completely, or make inferences about unavailable information based on the information they do have.</p> <p>Some aspects of comprehension may be influenced by information processing tendencies that are naturally associated with the central nervous system structure/function of humans. However, no explicit reference to any theoretical framework to explain how and why ‘format’ affects understanding, preferences, and choices.</p>

(Winterbottom, Bekker et al. 2008)	Balanced information about the advantages and disadvantages of all the treatment options.	Presentation of information in a way that enables individuals to process this information without bias.	<p>Rationale: It is likely that patient narratives encourage the use of heuristic processing. Processing information heuristically relies on the use of ‘rules of thumb’ based on an individual’s past experiences and observations (Chaiken 1980). In such circumstances, the context of the message, such as who is delivering the information, is more influential in decision making than the message content, such as information about the risks and benefits of treatment options (Chaiken 1980).</p> <p>No explicit reference to theoretical framework, but the above rationale refers to heuristic/systematic information processing model.</p>
(Zapka, Geller et al. 2006)	Complete and clear information; bias in selection and presentation of information	Not explicitly defined	No rationale provided other than stating that ‘what facts are presented to women about screening and how information is presented, is basic to informed decision-making’.
(Zikmund-Fisher, Ubel et al. 2008)	Balanced presentation of risks and benefits	<p>Not explicitly defined but seems to refer to:</p> <p>Presenting specific probability information regarding both good and bad health outcomes of their decisions and by describing these outcomes in imaginable and identifiable formats – leading to better comprehension and guarding against undesirable biases.</p>	<p>Rationale: A key aim of many decision aids is to modify patients’ unrealistic expectations (e.g., elevated beliefs about the likelihood of a good outcome), by presenting specific probability information regarding both good and bad health outcomes of their decisions and by describing these outcomes in imaginable and identifiable formats.</p> <p>In order to provide balance against patients’ natural inclination to focus on the benefits of potential medical treatments, a central part of many decision aids is a thorough discussion of the risks associated with interventions.</p>

1. The paper only mentions that balance is incorporated into the information dimension of the instrument. The paper describes the development of IPDASi, but there is no description of what balance constitutes.

Table 2. Methodological Comments About Balancing the Presentation of Options and Information in Patients' Decision Aids: A Summary of Relevant Empirical Papers

Author, Year	Ways of Enhancing Balance What techniques, if any, have been described that enhance balanced/unbiased presentation?
(Elwyn, O'Connor et al. 2006)	This paper highlights the risk of using patient stories, since these could introduce bias due to self-identification.
(Elwyn, O'Connor et al. 2009)	N/A
(Evans, Elwyn et al. 2007)	The presentation of uncertainty is an important but difficult task. Balance can be enhanced when presenting contrasting information, opinions and experiences. These authors highlighted the difficulty when dealing with sensitive issues.
(Feldman-Stewart, Brennenstuhl et al. 2007)	Imbalance appears when: 1) for treatment options there is no description of treatment procedures; and 2) more emphasis is given to false positives than false negatives. There is conflict between providing accurate information and overloading the patient with information. One solution is to label the numeric values as estimates and to provide further information about uncertainty when the patient requests it. Demonstrate how to up-date the information is by providing citations. Patient narratives should be avoided until the potential biasing effect is better understood.
(Griffith, Fichter et al. 2008)	The DA that included a "no screening option" was scored as less in favour of screening.
(Martin, Brower et al. 2011)	Graphical images that provide a visual representation of numbers (e.g., pictogram or speedometer) may support recall of probabilities.
(Roberts, Raynes-Greenow et al. 2004)	N/A
(Ubel, Smith et al. 2010)	Present contextual risk information (information on competing risks the patients would face over the next five years, such as risks of experiencing colon cancer, a heart attack, or all-cause mortality). However, the authors caution: "Is risk context information the solution to this problem? We think this would be premature...needs to be replicated before such an approach could be deemed a success...we do not have an adequate understanding of why contextual information about competing risks eliminated the order effect...our goal is not to convince DA developers that we have solved this problem...to encourage researchers to focus more efforts...." "Second, the order effects were small, and not necessarily of clinical significance."

<p>(Wills and Holmes-Rovner 2003)</p>	<p>Ways of eliminating bias/improving understanding/risk communication:</p> <ul style="list-style-type: none"> • Framing effects can sometimes be reduced/eliminated by presenting probabilities as “natural frequencies;” e.g. “1 in 10 people” • Understanding can potentially be improved by the use of absolute risk descriptions and by placing risks in context for a given patient. • There is also a need to tailor the format of risk communication to an individual’s level of numeracy (mathematical literacy), • In routine clinical encounters, careful attention should be paid to presenting “balanced” information in both positive and negative frames. • Graphics can improve the understanding of numerical probability information, by showing patterns that might not otherwise be recognized, facilitating numerical computations, and attracting attention to information. Drawbacks include the possibility that people may dislike some types of displays or may fail to comprehend the key points of graphics, and that graphics may actually detract from understanding. Unfortunately, the formats that might be favored by a number of people may also result in less appreciation or misunderstanding of information. • Understanding may also benefit from placing information in context; “risk ladders” and “action standards” may be reference points for decision making <p>Aside from the well-known heuristics/biases paradigm, few novel theoretical approaches have been proposed to improving comprehension of risk/benefit information.</p>
<p>(Winterbottom, Bekker et al. 2008)</p>	<p>No methodological comments provided.</p>
<p>(Zapka, Geller et al. 2006)</p>	<p>No methodological comments provided.</p>
<p>(Zikmund-Fisher, Ubel et al. 2008)</p>	<p>Including graphs in risk communications is essential to support an informed treatment decision-making process. Pictographs make risk statistics easier to interpret, reducing biases associated with incremental risk presentations.</p>

1. This paper only mentions that balance is incorporated into the information dimension of the instrument. The paper describes the development of IPDASi, but there is no description of what balance constitutes.

c) Emerging Issues/Research Areas in Theory/Rationale

- Theoretical and ethical challenges are created by the fact that decision aids do not exist in a vacuum. Patients (and clinicians) bring to the table many pre-existing biases. These biases can be based on misinformation, cognitive or affective heuristics and biases (e.g., availability bias resulting in aversion to one treatment option because of one case example that stands out in one’s mind—perhaps seen on the news media), or non-evidence based practice norms (e.g., only offering patients surgery despite evidence that observation and surgery are equivalent in terms of survival for men with low risk prostate cancer) (Wilt, Brawer et al. 2012).

- We acknowledge that there is debate about whether decision aids should strive for neutrality or in some situations attempt to counter or undo known biases. If the ultimate goal of medical decision making is to have patients make an informed decision based on balanced consideration of the options, an argument could be made that it is sometimes ethically appropriate for decision aids to not be balanced insofar as they are countering an existing bias so as to bring the patient to an overall balanced decision. For example, decision aids could describe misconceptions or non-evidence based practice patterns. The more generally accepted perspective is that developers should always strive for balance in the aids they produce. A helpful distinction might be made between decision aids and health promotion tools. The term “health promotion” is used to describe educational products that promote healthy behaviours (e.g., stopping smoking, use of sunscreen) for which there is consensus that these behaviours are generally good for people’s health.
- There is also ongoing debate about whether decision aids should always include a default, “do nothing” option when there is clear evidence of benefit associated with one or more specific options. In some situations, a “do nothing” option would not be supported by evidence. One reasonable response to this situation is to acknowledge that decision aids should provide information about the consequences of doing nothing while not presenting it as a reasonable option.

SECTION 5: EVIDENCE BASE UNDERLYING THIS QUALITY DIMENSION

a) Updated Evidence Base

Our Literature Search Strategy

A literature search of Ovid MEDLINE was performed for articles that reported information about the balance of patient decision aids, published since 1980. The following search terms were used: (decision aid or decision support) and (equitabl* or balanc* or neutral* or bias* or slant* or inequitabl* or unbiass or unbalanc*). The search led to 875 articles identified for review. We searched for studies that included samples of individuals who received a DA; thus studies without a control group (e.g., feasibility studies of DAs) could also be included.

Articles were coded as follows: 1, “Accept: clear evidence that balance/bias of patient decision aids, or other patient educational materials, is addressed;” 0, “Reject: no evidence that balance/bias of patient decision aids, or other educational materials, is addressed;” or 2, “Unsure: agreement to be established by review team.”

Of these 875 articles, 45 were coded as “accept”, of which 9 were later deemed irrelevant (6 were conference contributions, 1 dealt with modelling, 1 dealt with diagnostic tests, and 1 was a primer). Nineteen articles were coded as “unsure”, of which 2 were accepted, leaving 38 papers for abstraction.

In addition, all articles included in the 2009 Cochrane Collaboration’s Systematic Review of randomized controlled trials of patient decision aids were reviewed for any mention of the

search terms listed above, yielding 15 papers. Of the 15 Cochrane papers, 1 was relevant, and 2 additional papers (co-authored by a member of the research team) were identified. This increased the number of papers for abstraction to 41.

Our Appraisal of the Abstracted Papers

We examined these 41 papers from two perspectives:

1. We determined whether or not the balance of the relevant decision aids was assessed, and, when it was assessed, we determined how that assessment was carried out.
2. Among those papers in which the balance of the relevant decision aids had been assessed, we examined the extent to which the assessment of balance had been affected by using side-by-side tables in the relevant decision aids to compare and contrast the available options.

1. The Assessment of Balance

Among the 41 assessed papers, we searched the results sections for assessments of balance. Studies without a control group (e.g., feasibility studies of decision aids) were also included. 10 papers reported such assessments; see Table 3, column 1.

For each of these 10 papers, we computed the percentage of respondents who found the relevant decision aid completely balanced; see Table 3, columns 2 and 3. In all cases, the balance of the decision aid was exclusively assessed from the users'/patients' perspective.

Table 3. Ten Studies that Report Users' Ratings of the Balance of a Decision Aid

Author & Year	Sample size*	Subjects who reported the aid was balanced. n (%)	Was an evidence table included in the aid?	Was any table included in the aid?
(Mathieu, Barratt et al. 2010)	117	66 (57%)	no	no
(Smith, Trevena et al. 2010)	334	160 (48%)	no	no
(Griffith, Fichter et al. 2008)	106	17 (16%)	unclear	unclear
(Spunt, Deyo et al. 1996)	239	133 (56%)	unclear	unclear
(Anderson, Carter et al. 2011)	19	17 (89%)	no	yes
(Watson, Hewitson et al. 2006)	468	439 (94%)	no	yes
(Drake, Engler-Todd et al. 1999)	38	27 (71%)	yes	yes
(Lalonde, O'Connor et al. 2004)	16	13 (80%)	yes	yes
(van Tol-Geerdink, Stalmeier et al. 2006)	150	142 (95%)	yes	yes
(van Tol-Geerdink, Leer et al, in press)	153	147 (96%)	yes	yes

*Only studies with at least 10 subjects were included.

While studies tended to use a 5-point Likert-type scale, we found inconsistency in the response formats used. See Table 4.

Table 4. Summary of Decision Aid Studies in Which the Balance of the Aid was Assessed

Author Year	Decision context and how balance was considered.	Definition of “balance”.	Whose perspective was assessed?	Response categories for assessing balance.	Description of table contrasting options.	Results: How many rate as “balanced”?
(Anderson, Carter et al. 2011)	Equally emphasized downsides and benefits.	No definition offered.	22 women with ovarian cancer.	5-point scale in response to question about the presentation being balanced: <ul style="list-style-type: none"> • Strongly disagree • Disagree • Neutral • Agree • Strongly agree 	Table include benefits, side effects arguments, with some numbers.	17 of 19 participants rated aid as neutral (89%).
(Drake, Engler-Todd et al. 1999)	Open-ended question concerning fairness and balance during pilot test; in evaluation trial close-ended questions also concerning balance and fairness.	No definition offered. Implied that balance was equivalent to fairness.	21 women of advanced maternal age and 17 spouses.	5-point scale: <ul style="list-style-type: none"> • Clearly slanted to testing • Slightly slanted to testing • Completely balanced • Slightly slanted to no testing • Clearly slanted to no testing 	Worksheet format with risks presented using icon arrays.	84% women (N = 21) and 53% men (N = 17) chose “completely balanced.”
(Griffith, Fichter et al. 2008)	Primary measures: clarity and balance comparing video DA versions with and w/o explicit discussion of option to not be screened.	No definition offered.	Single sex volunteer focus groups. 12 groups at 3 sites, total of 106.	5-point scale: <ul style="list-style-type: none"> • Strongly in favor of screening • Somewhat in favor • Neither in favour nor against screening • Somewhat against • Strongly against 	No tables were used (according to author). Mentions comparison of the different tests, not clear if the “no screen” option is in the table.	16% rated aid is neither in favour nor against screening, for both versions.

(Lalonde, O'Connor et al. 2004)	Development of a DA to improve decision quality and adherence to chosen option.	No definition offered. Provided “balanced examples of how others go through the steps” (of making the decision)	16 patients receiving pharmacologic treatment for hypertension and/or dyslipidemia.	3-point scale: <ul style="list-style-type: none"> • Slanted towards lifestyle options • Slanted toward taking drugs • Balanced 	Risk of heart disease and stroke presented next to benefits using worksheet format.	80% rated aid as balanced (12 of 16).
(Mathieu, Barratt et al. 2010)	Effect of DA on knowledge and ability to make informed decision about mammogram screening at age 40. “(N)eed for balanced, evidence –based info that enables informed decision making.”	No explicit definition, but explains how to achieve balance. Present cumulative risks over an appropriate time frame, use diagrams for probabilities, use large denominators, show event rates as whole numbers, and provide context to consider the effect.	Women age 38-45 who accessed the website and met eligibility criteria (117 completed the acceptability questions).	5 point Likert scale: <ul style="list-style-type: none"> ▪ Clearly towards not screening ▪ A little towards not screening ▪ Completely balanced ▪ A little towards having screening ▪ Clearly towards having screening 	No table included.	49% (57) rated aid as completely balanced. 29% (34) rated aid as a little towards not screening.
(Smith, Trevena et al. 2010)	Balanced and fair information on bowel cancer screening.	No definition offered.	334 adults aged between 55 and 64 with low education attainment eligible for bowel cancer screening.	Not mentioned.	No, risks on separate pages, mix of two- and multicolour risk figures.	48% (160) rated aid as completely balanced.
(Spunt, Deyo et al. 1996)	Balance: completely balanced (if the patients found the program to be balanced).	No definition offered.	239 patients affected with low back pain.	5-point scale: <ul style="list-style-type: none"> • Clearly slanted-- surgery • Slightly slanted—surgery • Completely balanced • Slightly slanted-- nonsurgical therapy • Clearly slanted-- nonsurgical therapy. 	Author did not respond to query use of table format.	56% (133) rated it “completely balanced.”

(van Tol-Geerdink, Stalmeier et al. 2006)	Was the information presented in a structured and balanced way?	No definition offered.	150 prostate cancer patients.	5-categories: <ul style="list-style-type: none"> • Clearly in favor of lower dose • Somewhat in favor of lower dose • Balanced • Somewhat in favor of higher dose • Clearly in favor of higher dose 	Probabilities of outcomes presented side-by-side using pie charts.	95% (142) choose balanced in DA group.
(van Tol-Geerdink, Leer et al. submitted)	Was the information presented in a structured and balanced way?	No definition offered.	240 patients with prostate cancer choosing between surgery or radiotherapy.	4-categories: <ul style="list-style-type: none"> • Yes, the information was balanced • No, in favour of surgery • No in favour of brachytherapy • No, in favour of external beam radiotherapy 	Probabilities of outcomes presented in an evidence table using pie charts.	96% (147 of 153) chose balanced option.
(Watson, Hewitson et al. 2006)	RCT of a decision aid about PSA testing. Assessed whether the information in the aid was presented in a “balanced way.” Also used a measure of decisional balance as a measure of attitudes toward PSA testing.	No definition offered.	Men from 11 GP practices, recruited through computerized registries.	Not fully stated. One option was, information was presented in a “balanced way.”	Aid included a summary of the potential benefits and downsides of testing. Information presented as a side-by-side figure/ table.	94% of 468 respondents rated the information in the aid as presented in a “balanced way.”

2. The Impact of Using Side-by-Side Tables to Contrast the Options

For each of these 10 papers, we also examined the papers—or their corresponding decision aids, if available—for the presence of tables contrasting the options. (Authors were contacted if a decision aid could not be found; two authors did not respond.)

Two general categories of tables were discerned; see Table 3, columns 4 and 5.

“Evidence tables” were defined as presenting probabilistic information on the pros and cons of options in a table. Such tables contain n columns with the options times m medical outcomes for the pros and cons, the $n*m$ cells containing frequency of occurrence (e.g., “x out of 100 had the outcome”, either with or without a visual aid to depict x out of 100) in the cells. Empty cells, to denote lack of risk information, would also be considered as valid cells. An example can be found in van Tol-Geerdink, 2006, Figure 1.

“Any table” was defined as either a) the presence of an evidence table, as defined above, or b) the presence of any other table contrasting the options—for example, when cells contained arguments.

Thus, we have separate “samples” of studies—one sample of studies that evaluated decision aids that incorporated a table, and another sample of studies that evaluated decision aids that did not incorporate a table.

These samples were compared—using a random effects model to take into account heterogeneity across studies—in terms of the percentages of patients who agreed that the relevant decision aid was balanced. We used univariate ANOVA, which used weighted least squares, and again weighted by the number of patients in the samples. With this conservative method of weighting, the analysis was based on the number of studies in a “sample”, and not on the number of patients included. All analyses were performed with SPSS (version 18.0).

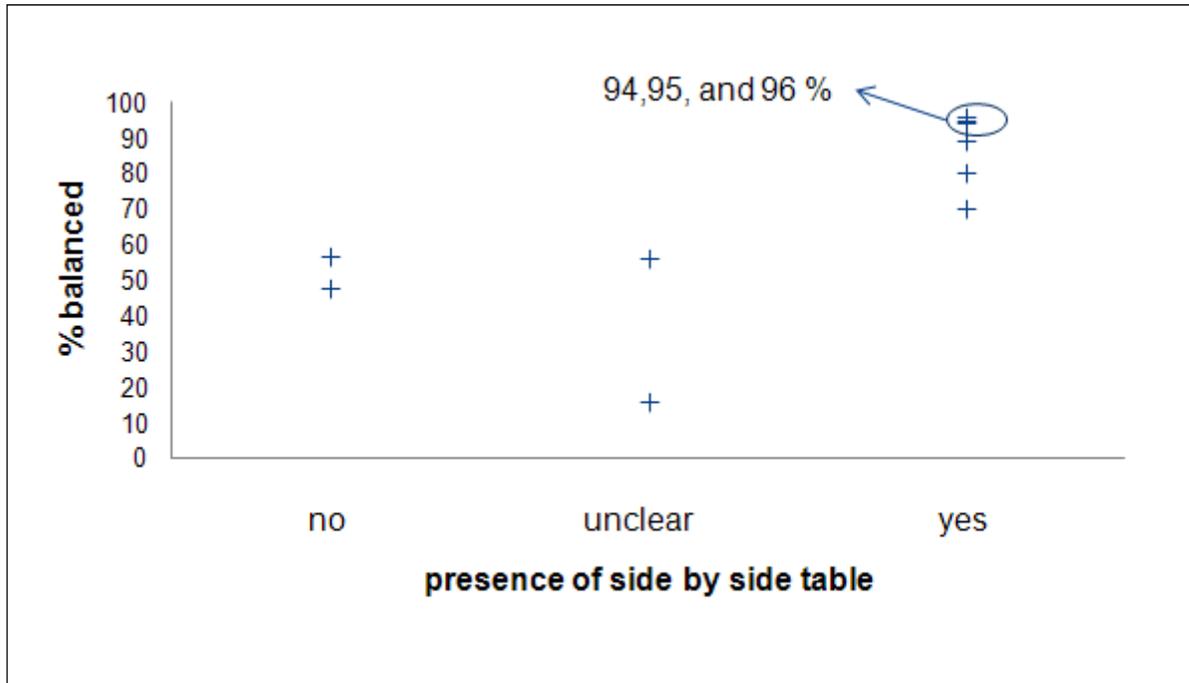
The results are depicted in Figure 1.

The results show that decision aids with “any table” received the highest ratings as being balanced ($F(2,7) = 21.18, p = 0.001$). Thus, the inclusion of a summary table of any kind in which the options are compared was associated with more subjects (ranging from 70% to 96%) judging the information as balanced.

The results also show that the inclusion of a specific “evidence table”, in which the options were compared using percentages, was not associated with patients being more or less likely to rate an aid as balanced ($F(2,7) = 2.77, p = 0.130$). Evidence tables were consistently rated as balanced by more than 70% of the respondents (see Table 3).

Support for the effectiveness of tables regarding gist and verbatim understanding of probabilities information, when compared to other formats, has been reported by several researchers (Tait et al., 2010; Hawley et al., 2008).

Figure 1. Percent of Subjects Rating a Decision Aid as Balanced, Stratified by Use of a Side-by-Side Table Contrasting the Options



b) Changes from the Original Evidence Base

The original evidence review for this chapter identified 97.7% of articles in the 2003 review of decision aid studies as presenting information about potential harms and well as potential benefits. Far fewer -- only 8% -- assessed the degree of balance in the aid from the user's perspective.

c) Emerging Issues/Research Areas in Evidence Base

- There is a need to develop a consensus on the definition of “balance” and on the methods used to assess balance.
- There is a need to carry out a range of comparative studies:
 - We should investigate whether different approaches to assessing balance lead to different evaluations of a decision aid. For example, asking patients if a decision aid is biased may lead to different responses than asking patients if they feel the information was presented fairly.

- We should compare different ways to improve the presentation of balanced information (e.g., using side-by-side tables).
 - We should compare the effects on balance ratings of various side-by-side tables in patients' decision aids, using human factors studies.
- The relatively good performance of evidence tables supports the use of traditional decision analytic reasoning using outcomes and their probabilities (expected utility) as a basis of supporting decision making in patients.

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**APPENDIX:
ORIGINAL CHAPTER I**

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Original Rationale/Theory

The goal in patient decision making is to enable the patient to make an informed autonomous decision that reflects their personal preferences. To this end, patient decision aids provide patients with information about options and their consequences (benefits/harms) to help them clarify personal preferences. However, the of an autonomous decision also implies that the presentation of information should not favor a specific option (Hope, 1996). There is empirical evidence that variations in the presentation of information affects how health is perceived, and how therapeutic choices are made and acted upon (Herrin, 2001; Jorgensen & Gotzsche, 2004). For example, depending on the framing of the data (e.g. using mortality or survival rates), patients make different treatment choices (Bohmer RM 2003). Furthermore, the way in which information is presented influences patients' satisfaction, knowledge, understanding, participation in decision-making, continuance of chosen options, coping with their situation, and search for further information (Broyles, Sharp et al. 1992; Inglis and Farnill 1993; Phatouros and Blake 1995; Christensen-Szalanski JJ 1997; Michie, Smith et al. 1999)

When unbalanced, information can create therapeutic expectations that are impossible to meet, and can lead patients to unwittingly undertake interventions that carry chances of harms that they would not willingly accept. Since it is not only dishonest but unethical to create unrealistic expectations or to obscure the chances of harm (Raffle 1997; Raffle 2000; Raffle 2001), patient decision aids must aim to present information in a balanced manner that does not inadvertently persuade the user to accept or reject a particular option.

Original Evidence

Inventory of Available Patient Decision Aids

Balanced presentation of information was assessed in patient decision aids registered in the Cochrane Review inventory (O'Connor, Stacey et al. 2003). Of 131 patient decision aids that were available and updated within the last 5 years:

- 97.7% (of 131) presented potential harms as well as potential benefits;
- 8.0 % (of 131) measured the degree of balanced presentation of benefits and harms from the user perspective; of these, the majority of patients found the patient decision aid balanced;

RCTs Involving Patients Facing Actual Choices

Of the 29 individual patient decision aids, evaluated in 34 RCTs included in the Cochrane Review, 19 were available for review of content (O'Connor, Stacey et al. 2003). Of these:

- All 19 (100%) presented potential harms as well as potential benefits;
- 4 (21%) measured the degree to which patients thought the presentation of benefits and harms was balanced. Three of these four reported that more than 2/3 of patients found the information balanced (see table 10.1). All four studies used a scale that was similar to the scale first reported by Barry and colleagues (1995).

Other Evaluative Studies

In 1995, Barry and colleagues asked men to indicate whether the information in a patient decision aid about the treatment of benign prostatic hyperplasia was slanted toward surgery, balanced, or slanted toward watchful waiting. Ratings were obtained on a five-point scale. As reported in table 10.1, 74% thought the patient decision aid was completely balanced. Of those who thought it was slanted, most indicated that it was slanted in the same direction to which they were leaning, which raises questions about the ability to accurately measure patients' perspective of information balance.

Barry et al.'s acceptability tool was also used in developing breast screening patient decision aids for women in out-of-target age groups (women 40 to 49 and women 70 and older) (O'Connor, Stacey et al. 2003; Jorgensen and Gotzsche 2004). Women within the target age group as well as practitioners affiliated with breast screening programs reviewed the patient decision aids. About half of the women found the patient decision aids slanted in favour of starting screening (40 to 49) or continuing screening (70 and older), while the others found them balanced. In contrast, several practitioners thought the patient decision aids were slanted against screening. These conflicting observations reinforce the uncertainty about whose perspective "counts" when assessing information balance and the challenges in obtaining an objective measure of balance.

(Jorgensen and Gotzsche 2004) conducted a cross sectional study of mammographic screening information presented by major interest groups on 27 Scandinavian and English websites to determine if there were balanced accounts of screening's possible benefits and harm. They found that most websites omitted information about important harms and emphasised benefits in a way that would be expected to increase uptake of screening. For example, 12 sites mentioned the lifetime risk of developing breast cancer, usually followed by the annual number of diagnoses. In contrast, only three sites mentioned that women have a more than 50% chance of surviving breast cancer and only four stated that the lifetime risk of dying from breast cancer is about 3-4%.

Original Table: Results of Evaluations of Balanced Presentation of Information Presented in Patient Decision Aids

	Evaluation	Clearly slanted to favour most invasive intervention	Slightly slanted to favour most intensive	Completely Balanced	Slightly slanted to no favour	Clearly slanted to NOT favour invasive intervention
Barry et al., 1995 BPH treatment	N = 373; prospective cohort study	1%	7%	74%	14%	4%
O'Connor et al., 1998; HRT	N = 81; within RCT	Not reported	Not reported	76%	Not reported	Not reported
Phelan et al., 2001; Back surgery	N = 41; within RCT	Not reported	Not reported	60%	Not reported	Not reported
Volk et al., 1999; PSA testing	N = 80; within RCT	6%	10%	79%	4%	1%

Original Appendix 1: Measuring Balanced Presentation

- a) When measuring the degree of balance in the presentation of options and consequences (benefits, harms), the users' (patients, practitioners) personal predisposition towards an option be elicited at baseline.
- b) For only two options:
A single question can be used to ask users (patients/practitioners) to rate whether the decision aid is slanted from strongly favouring option A through completely balanced to strongly favouring option B. For example:
How balanced and fair did you find the information presented in the decision aid (please check one)?
- Clearly slanted to option A
 - Slightly slanted to option A
 - Completely balanced
 - Slightly slanted to option B
 - Clearly slanted to option B
- c) For three or more options, there are two approaches that could be used to measure balance.
- a. For each option presented, ask users to rate whether the decision aid is strongly in favour of that one specific option through balanced to strongly in favour of the other options. For example:
How balanced and fair did you find the information presented in the decision aid (please check one)?
- Clearly slanted to option A
 - Slightly slanted to option A
 - Completely balanced
 - Slightly slanted to the other options
 - Clearly slanted to the other options
- b. Ask users to respond to a single question as an indication of biasing the user in one direction. For example:
Did the program present one option as the best overall choice?
- Yes
 - No

Original Appendix 2: Interpreting the Results of Balance

- a) Calculate the percentage of users who rate it as completely balanced.
- b) Check the distribution of options that were identified as not balanced. If the users are roughly equally scattered, this implies that the patient decision aid offers a balanced presentation. If there is agreement that the patient decision aid is slanted either consistently toward or consistently against an option, it is likely that the presentation of information needs to be revised. However, before making revisions, it is important to consider users baseline choice predisposition. Previous evaluation has found that users who already have a preferred option in advance of seeing a patient decision aid are more

likely to rate it as “slanted” either in the same direction or away from their own preferences. They may have found the arguments that support their views to be more compelling or they may not have wanted to be made aware of or reminded of facts that are counter to their choice.

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