

review title

Decision aids for people facing health treatment or screening decisions

(O'Connor et al. 2009)

focus of the review

The aim of this Cochrane review was to evaluate the efficacy of decision aids for people facing difficult treatment or screening decisions.

- *Decision aid* formats included written information, video, audiotape, interactive multimedia, and personal decision exercise or coaching, or combinations of formats.
- *Participants* included people facing prostate cancer screening, genetic testing, vaccination, HRT, surgery.

key results of the review

What this review shows about decision aids for people facing treatment or screening decisions:

Decision aids compared with usual care:

- Improve knowledge and accuracy of risk perceptions; increase patient-controlled decision-making;
- Reduce the number of people remaining undecided and decisional conflict; decrease the uptake of major surgery;
- May improve confidence, satisfaction with participation in decision making, vaccination uptake.

Detailed decision aids compared with simple:

- Improve knowledge and accuracy of risk perceptions;
- May improve congruence between values and the option chosen.

What this review does not show about decision aids for people facing treatment or screening decisions:

Decision aids compared with usual care: there is insufficient evidence to determine the effects on:

- Shared decision making, value congruence with the option chosen and realism of expectations.

Detailed compared with simpler decision aids: there is insufficient evidence to determine effects on outcomes including:

- Realism of expectations, decisional conflict, participation in decision making, and specific screening, surgery and treatment decisions.

Decision aids compared with usual care, or detailed versus simple versions: there is insufficient evidence for outcomes including:

- Recognition of need for a decision and the role of values in decision making; physical, psychological and psychosocial outcomes; costs, and consultation length and quality.

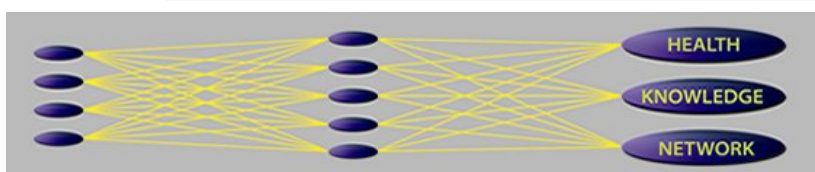
This Evidence bulletin is produced by the Centre for Health Communication and Participation, for the Health Knowledge Network, with funding from Statewide Quality Branch, Department of Human Services, Victoria, Australia.

This bulletin summarises a recently published Cochrane systematic review

This page highlights key aspects of the review

Pages 2-5 summarise the review

The evidence table on pages 6-10 contains more detail of the review



Background to the review

Making a decision about health can be a complex process. There may be many treatment options; or the effectiveness and safety of the different options may not be clear. A clear 'best' choice for health care treatment, in terms of benefits and harms for any one person may not exist.

Decision aids are a type of decision support intervention designed to help people make specific choices about their health from a range of possible options. They can be used before, during or after visits to the clinical practitioner and enable patients be more active and informed decision makers. They focus specifically on the options and outcomes available, and aim specifically to prepare people to make a deliberate, personal choice.

Decision aids such as pamphlets, booklets, CD-ROMs or interactive video disc aim to help people understand the likely outcomes of different choices; to consider these outcomes in terms of their personal preferences; to enable people to arrive at a decision; and to help them to feel supported in their decision making.

At a minimum, decision aids provide information on the options available and outcomes relevant to a person's health. They may also provide information on the disease itself; exercises to help people clarify their values and preferences about treatment or screening options; costs associated with different options; structured guidance on decision making and communication; information about other people's opinions; or information about the probabilities of particular outcomes on the basis of personalised risk factors.

This 2009 update of a review examined the effects of decision aids for people facing health or screening decisions.

Trials included in the review

The review included 55 randomised controlled trials (RCTs); involving over 16,000 participants.

Interventions were directed to consumers—people making decisions about screening or treatment for themselves, a child or an incapacitated significant other.

A wide range of treatment decisions (including those relating to hormone replacement therapy, hepatitis B vaccination, prostate cancer treatment and BPH treatment) and screening decisions (including those relating to prostate cancer (PSA) screening, genetic testing, colorectal cancer screening and prenatal screening) were included in the review.

Trials were undertaken in Australia, Canada, China, Finland, The Netherlands, United States and United Kingdom.

Description of interventions

Decision aids are evidence-based interventions designed to help people participate in making specific and deliberate choices from among different healthcare options in ways that reflect their preferences.

Examples of decision aids included in this review's included trials are:

- Interactive video disc on options' outcomes, clinical problems, outcomes probability, and others' opinions;
- Pamphlet on options' outcomes, clinical problem, outcome probability, values clarification, and guidance/coaching;
- Video plus pamphlet; and,
- CD-ROM plus counselling.

Description of outcomes

Primary outcomes of interest to review authors specified in advance included:

- Attributes of the decision (knowledge, accuracy of risk perception);
- Attributes of the decision process (eg. understanding that values affect decisions);
- Decisional conflict, knowledge;
- Patient-practitioner communication;
- Participation in decision making.

Secondary outcomes included:

- Behaviour (decisions, adherence);
- Health outcomes (health status, quality of life, depression, emotional distress);
- Healthcare system (costs, consultation length).

What the review shows: summary of key findings:

In relation to the comparison:

Decision aids versus usual care

There is sufficient evidence from trials that decision aids:

- Significantly increased **knowledge** (18 trials, 3491 participants);
- Significantly increased accuracy of **risk perceptions** (8 out of 9 studies showed significant increases). The increase in accuracy was larger when risk information was presented in numbers compared with words;
- Reduced total **decisional conflict** (10 trials, 1850 participants); and all decisional conflict subscale measures except the uncertainty subscale measure;
- Reduced the proportion of people remaining **undecided** (4 trials, 1032 participants);
- Increased patient-controlled **decision making** (7 trials, 1106 participants) and decreased practitioner-controlled decision making (8 trials, 1277 participants);
- Decreased the **rate of major elective surgery** (8 trials, 2069 participants);
- Decreased the rate of **PSA screening** uptake (5 trials, 1442 participants).

Decision aids versus usual care (cont'd)

There is some evidence from trials that decision aids:

- May increase the **uptake** of hepatitis B vaccination (1 trial, 1280 participants; 76% increase in uptake) and improve confidence to make decisions (2 studies of 3);
- May improve **satisfaction** with opportunities to participate in decision making and with the overall results of treatment (1 trial, 625 participants).

In relation to the comparison:

Detailed decision aids versus simple decision aids

There is sufficient evidence from trials that detailed decision aids:

- Significantly increased **knowledge** (9 trials, 1261 participants);
- Significantly increased accuracy of **risk perceptions** (3 out of 3 studies showed significant increases).

There is some evidence from trials that detailed decision aids:

- May significantly improve **congruence of values** with chosen option (2 trials).

What the review does not show

In relation to the comparison:

Decision aids versus usual care

There is insufficient evidence from trials to decide between decision aids and usual care with respect to:

- **Realism of expectations, satisfaction** with the decision or the decision making process, satisfaction with the information provided, with preparation for **decision making** or with genetic counselling;

Decision aids versus usual care (cont'd)

There is insufficient evidence from trials to decide between decision aids and usual care with respect to:

- **Shared decision making** or congruence of **values** with chosen option;
- General or specific **health outcomes**, anxiety, depression, or continuance with the chosen option;
- Uptake of other specific options, including colon cancer **screening**, breast cancer genetic **testing**, prenatal testing, hormone replacement therapy, minor elective **surgery**, use of specific **medications** (antithrombotic therapy, antihypertensive medication), preference for adjuvant chemotherapy for breast cancer treatment, birth options after caesarean delivery or autologous blood donation;
- **Consultation length** and quality (including perceived usefulness and directiveness), or costs and resource use.

These outcomes were not measured by trials:

- Preference-linked outcomes, recognition of the need for a decision and the role of values, decisional regret, or discussion of values with professional.

Harms and adverse effects

Not assessed directly. Decision aids do not appear to have any consistent effects on associated outcomes such as anxiety, health outcomes, or satisfaction.

What the review does *not* show (cont'd)

In relation to the comparison:

Detailed decision aids versus simple decision aids

There is insufficient evidence from trials to decide between detailed and simple decision aids with respect to:

- Total decisional conflict or any decisional conflict subscale measures (uncertainty, uninformed, unclear values, unsupported, or ineffective choice subscales);
- Participation in decision making, proportion of people remaining undecided, satisfaction with the decision making process, decisional regret or confidence;
- Specific choices: surgery over conservative treatment option, PSA screening uptake or prenatal diagnostic testing;
- General or specific health outcomes, anxiety, continuance with the chosen option or realism of expectations;

These outcomes were not measured by trials:

- Depression, costs, consultation length or quality, satisfaction with the decision, preference-linked outcomes, recognition of the need for a decision and the role of values, or discussion of values with professional.

Harms and adverse effects

Not assessed directly. Decision aids (detailed/simple) do not appear to have any consistent effects on associated outcomes such as anxiety, health outcomes, or satisfaction.

Conclusions

Review authors conclude that there are positive effects of decision aids in facilitating active participation and informed decision making and that this may be sufficient evidence for using them in clinical practice. However, if decision aids are to be implemented successfully they need to be of good quality and relevant to the population, practitioners must be willing to use them, effective support for delivery should be in place, and both consumers and practitioners must be skilled in using them.

Summary of
the review
continued...

See the
Evidence table
and
key to results
on pages 6-10

Recommendations from authors

Authors recommend that there is a need to better understand interactions between the use of decision aids by patients and patterns of communication between patients and providers, and to assess the effects of wider range of decision aid features.

Authors also recommend that there is a need to determine the essential components of an effective decision aid, to identify those groups of people who may most benefit from detailed

versions of the intervention, and to assess the effectiveness of different components of aids on decision support in different clinical contexts and different populations.

Authors recommend that a broader range of outcomes be examined for decision aids, and they highlight the need for research to identify determinants and to promote the uptake and use of decision aids in different clinical settings.

Forwarding

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Forwarding
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This table is part of an overview of the review created by Dr Rebecca Ryan, at The Consumers & Communication Review Group, La Trobe University. It contains detailed data extracted from the review. The summary on the previous pages of this EVIDENCE bulletin draws on content from both this table and the review. This table uses standardised wording developed by the Review Group. A key to this wording follows the table and should be used to interpret the data.

Review title: Decision aids for people facing health treatment or screening decisions
 Authors: O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D.

Description of main features

Aim: To evaluate the efficacy of decision aids for people facing difficult treatment or screening decisions.

Trial design: RCT.

Participants:

Included: People making decisions about screening or treatment for themselves, a child or an incapacitated significant other. A wide range of treatment and screening decisions were included. Screening decisions included those relating to prostate cancer (PSA) screening (8 trials), genetic testing (5), colorectal cancer screening (3), prenatal screening (3). Treatment decisions included those relating to hormone replacement therapy (9 trials), hepatitis B vaccination (1), prostate cancer treatment (2) and BPH treatment (2).

Interventions:

Included: Decision aids aim to improve decision making by patients, and are defined as evidence-based tools designed to prepare people to participate in making specific and deliberated choices from among different healthcare options in ways that reflect their preferences. In general, decision aids provide evidence-based information about a condition, options and associated benefits and harms, probabilities and uncertainties; help people to recognise that the decision is value-sensitive and to clarify (implicitly or explicitly) the value that they place on the benefits, harms and uncertainties of the option; and to provide structured guidance in decision making and communicating their informed values with others involved in the decision. Decision aids must provide, at least, information on the available options plus outcomes of relevance to the person's health, as well as implicit ways to clarify a person's values. Decision aids may also have included information on: the disease or condition; others' opinions; costs associated with different options; the probabilities of particular outcomes based on assessment of the individuals' risk factors; explicit values clarification exercise; personalised recommendations on the basis of clinical characteristics and expressed preferences; or guidance in the stages of decision making and in communicating with others.

Excluded: Interventions focussing on decision-making about lifestyle changes, clinical trial entry or advance directives (for situations in which the person becomes unable to participate in decision-making in the future), educational programs not associated with a specific decision, and interventions designed to promote adherence or to gain informed consent for a recommended option.

Comparison arms:

- Decision aids versus usual care
- Detailed decision aids versus simple decision aids

Outcomes:

Included and specified in advance:

Primary outcomes: attributes of the decision (knowledge, accuracy of risk perception, agreement between values and chosen option) and the decision process (recognition of the need for the decision, knowledge of options and characteristics of these, understanding that values affect decisions, clarity about which characteristics of the options matter most, discussion of their values with their practitioner, becoming involved in ways that the person prefers), decisional conflict, knowledge,

patient-practitioner communication, participation in decision making and satisfaction.
Secondary outcomes: behaviour (decisions, adherence to chosen option), health outcomes (health status and quality of life, anxiety, depression, emotional distress, regret, confidence), and healthcare system (patients' and physicians' satisfaction, costs, consultation length, litigation rates).

Number of trials included: 55 [assessing 51 individual decision aids for 23 distinct treatment or screening decisions] [A further 15 studies are ongoing and await assessment].

Types of trials included: RCT

Number of participants included: >16,000

Meta-analysis performed: 55 [assessing 51 individual decision aids for 23 distinct treatment or screening decisions] [A further 15 studies are ongoing and await assessment].

Review methods:

Standard Cochrane Collaboration review methods were used, including the following: a priori research design provided; extensive searching including searching for unpublished studies; selection criteria were specified in advance and applied; list of included and excluded studies provided; quality criteria for assessment of included studies were reported and applied; methods of analysis were reported; conflict of interest stated.

Quality:

Included trials:

Rated using the Jadad scale (based on randomisation, blinding and description of withdrawals) plus an assessment of adequacy of allocation concealment. Quality of included studies was generally moderate: all were randomised, none were blinded, and description of loss to follow up was rated as generally good. Allocation was rated as adequately concealed in 33/55 studies (rated unclear in 15/55).

Review AMSTAR rating (out of possible 11): 10 - high quality review.

Comments: The review methods adequately met all items of the AMSTAR checklist: although publication bias was not formally assessed (statistically) the likelihood of publication bias was explicitly addressed as a possible source of bias by the review.

Setting: Country:

Australia, Canada, China, Finland, The Netherlands, United States and United Kingdom. Intervention setting: not stated.

Recipient: Interventions directed to the consumer.

Provider: Variable, decision aids ranged from internet-based aids to face to face discussions/ counselling. The majority were self-administered by the patient, some were delivered by or in conjunction with practitioners.

Format: Variable, decision aids were delivered in one or more (combinations) using the following formats: pamphlet, booklet or leaflet; written information, workbook or worksheet, decision board, scripted information, video, audiotape, CD-ROM, interactive multimedia, decision analysis, counselling (group or individual), lecture, personal decision exercise or coaching.

Intervention	Results of review
Decision aids versus usual care	<p>Sufficient evidence from trials that compared with usual care:</p> <ul style="list-style-type: none"> • Decision aids significantly increased knowledge (18 trials, 3491 participants) (MD 15.2, 95% CI 11.7, 18.7). • Decision aids significantly increased accuracy of risk perceptions (8 out of 9 studies showed significant increases; RR estimates ranged from 1.31 to 5.28). The increase in accuracy was larger when risk information was presented in numbers, when compared with risk information presented in words. • Decision aids reduced total decisional conflict (10 trials, 1850 participants) (MD -6.1, 95% CI -8.6, -6.6); and all decisional conflict subscale measures (uninformed, unclear values, unsupported, and ineffective choice subscales) except the uncertainty subscale measure. • Decision aids reduced the proportion of people remaining undecided (4 trials, 1032 participants) (RR 0.51 95% CI 0.3, 0.8). • Decision aids increased patient-controlled decision making (7 trials, 1106 participants) (RR 1.7, 95% CI 1.02, 2.7) and decreased practitioner-controlled decision making (8 trials, 1277 participants) (RR 0.6, 95% CI 0.5, 0.8). • Decision aids decreased the rate of major elective surgery (8 trials, 2069 participants) (RR 0.8, 95% CI 0.6, 0.9). • Decision aids decreased the rate of PSA screening uptake (5 trials, 1442 participants) (RR 0.8, 95% CI 0.7, 0.98). <p>Some evidence from trials that compared with usual care:</p> <ul style="list-style-type: none"> • Decision aids may increase the uptake of hepatitis B vaccination (1 trial, 1280 participants; 76% increase in uptake) and improve confidence to make decisions (2 studies of 3). • Decision aids may improve satisfaction with opportunities to participate in decision making and with the overall results of treatment (1 trial, 625 participants) (OR 1.5, 95% CI 1.1, 2). <p>Insufficient evidence from trials to decide between decision aids and usual care with respect to:</p> <ul style="list-style-type: none"> • Realism of expectations, satisfaction with the decision or the decision making process, satisfaction with the information provided, with preparation for decision making or with genetic counselling. • Shared decision making or congruence of values with chosen option. • General or specific health outcomes, anxiety, depression, or continuance with the chosen option. • Uptake of other specific options, including colon cancer screening, breast cancer genetic testing, prenatal testing, hormone replacement therapy, minor elective surgery, use of specific medications (antithrombotic therapy, antihypertensive medication), preference for adjuvant chemotherapy for breast cancer treatment, birth options after caesarean delivery or autologous blood donation.

Intervention	Results of review
Decision aids versus usual care (continued)	<p>Insufficient evidence from trials to decide between decision aids and usual care with respect to:</p> <ul style="list-style-type: none"> • Consultation length and quality (including perceived usefulness and directiveness), or costs and resource use. • Preference-linked outcomes, recognition of the need for a decision and the role of values, decisional regret, or discussion of values with professional. <p><u>Harms and adverse effects:</u> Not assessed directly. Decision aids do not appear to have any consistent effects on associated outcomes such as anxiety, health outcomes, or satisfaction.</p>
Detailed decision aids versus simple decision aids	<p>Sufficient evidence from trials: compared with simple decision aids:</p> <ul style="list-style-type: none"> • Detailed decision aids significantly increased knowledge (9 trials, 1261 participants) (MD 4.6, 95% CI 3.0, 6.2). • Detailed decision aids significantly increased accuracy of risk perceptions (3 out of 3 studies showed significant increases; RR estimates ranged from 1.46 to 1.54). <p>Some evidence from trials: that compared with simple decision aids,</p> <ul style="list-style-type: none"> • Detailed decision aids, significantly improve congruence of values with chosen option (2 trials). <p>Insufficient evidence from trials: to decide between detailed and simple decision aids with respect to:</p> <ul style="list-style-type: none"> • Total decisional conflict or any decisional conflict subscale measures (uncertainty, uninformed, unclear values, unsupported, or ineffective choice subscales). • Participation in decision making, proportion of people remaining undecided, satisfaction with the decision making process, decisional regret or confidence. • Specific choices: surgery over conservative treatment option, PSA screening uptake or prenatal diagnostic testing. • General or specific health outcomes, anxiety, continuance with the chosen option or realism of expectations. • Depression, costs, consultation length or quality, satisfaction with the decision, preference-linked outcomes, recognition of the need for a decision and the role of values, or discussion of values with professional. <p><u>Harms and adverse effects:</u> Not assessed directly. Decision aids (detailed/ simple) do not appear to have any consistent effects on associated outcomes such as anxiety, health outcomes, or satisfaction.</p>

The table on this page presents the standardised wording that should be used to interpret the data in the results section of the EVIDENCE table on the previous pages.

SUMMARY STATEMENT	TRANSLATION
Sufficient evidence from trials	<p>Evidence to support conclusions about the effect of the intervention(s) in relation to a specific outcome(s). This includes evidence of an effect in terms of:</p> <ul style="list-style-type: none"> • benefit or • harm. <p>Statistically significant results are considered to represent sufficient evidence to support conclusions, but a judgement of 'sufficient evidence' is also based on the number of trials/ participants included in the analysis for a particular outcome.</p> <p>A grading of 'sufficient evidence' is often based on meta-analysis producing a statistically significant pooled result that is based on a large number of included trials/ participants.</p> <p>This judgement may also be made based on the number of trials and/or trial participants showing a statistically significant result - for example (in a narrative synthesis) a result where 12 trials of a total of 14 for a specific outcome showed a statistically significant effect of an intervention would be considered to represent 'sufficient evidence.'</p>
Some evidence from trials	<p>Less conclusive evidence to make a decision about the effects of a particular intervention(s) in relation to a specific outcome(s).</p> <p>This may be based on narrative syntheses of review results. In this case, the result is qualified according to the findings of the review - for example, 'some evidence (5 trials of 9) reported a positive effect of'</p> <p>{This would be based on a more equivocal set of results than those obtained for 'sufficient evidence' above. For example, while 12/14 statistically significant trials would be classed as 'sufficient evidence', 5/9 statistically significant trials is more equivocal and would be classes as 'some evidence.'}</p> <p>This may also be based on a statistically significant result obtained in a small number of trials; or a statistically significant result obtained from trials with a small number of participants.</p>
Insufficient evidence from trials	<p>Not enough evidence to support conclusions about the effects of the intervention(s) on the basis of the included trials. This should be interpreted as 'no evidence of effect', rather than 'evidence of no effect'.</p> <p>Statistically non-significant results are considered to represent insufficient evidence.</p> <p>Where the number of trials is small, and/or the number of participants included in the trials is small, 'insufficient evidence' might reflect underpowering of the included trials to be able to detect an effect of the intervention.</p> <p>Where the number of trials is large, and/or the number of participants included in these trials is large, 'insufficient evidence' may reflect underlying ineffectiveness of the intervention to affect the outcomes being examined.</p>
Insufficient evidence in relation to measurement	<p>Not enough evidence to support conclusions about the effects of the intervention due to a lack of reporting on the specified outcomes.</p> <p>This can be the result of :</p> <p>(i) the review electing not to report on a particular outcome, or set of outcomes, despite being reported by the included trials; or</p> <p>(ii) the review was not able to report on the outcome, as data for the outcome was not reported by the included trials. Note: used for reporting against outcomes only.</p>
N/A	<p>Not applicable to the outcome category of interest. Note: used for reporting against outcomes only.</p>