

A systematic review on communicating with patients about evidence

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Abstract

Objective To conduct a systematic search for (1) the effectiveness of evidence-based communication tools to increase patient understanding of evidence, (2) effective formats for representing probabilistic information and (3) effective strategies for eliciting patient preferences about evidence. A case scenario is used to illustrate some of the difficulties of putting these results into practice. **Data sources** Systematic search of The Cochrane Library, Medline, Psychinfo, Embase and Cancerlit. **Review methods** Systematic reviews of randomized controlled trials (RCTs) and high quality RCTs were included. Studies were excluded if they did not address the question, were focused on behavioural outcomes without attempting to increase understanding, were concerned with counselling as a therapeutic intervention, or were specific to communication regarding clinical trial participation. **Results** We found 10 systematic reviews of RCTs and 30 additional RCTs addressing our questions. Communication tools in most formats (verbal, written, video, provider-delivered, computer-based) will increase patients' understanding but are more likely to do so if structured, tailored and/or interactive. Probabilistic information is best represented as event rates (natural frequencies) in relevant groups of people, rather than words, probabilities or summarized as effect measures such as relative risk reduction. Illustrations such as cartoons, or graphs (vertical bar charts) appear to aid understanding. Values clarification exercises may be better than standard utility techniques for eliciting preferences in individual decision making. Looking for effective evidence-based communication tools for prostatic specific antigen testing highlighted the challenges for clinicians and consumers in accessing tools that are evidence-based in design as well as content. **Conclusion** There is an increasing body of evidence supporting the design of effective evidence-based communication tools but variable access to such tools in practice.

Case scenario: *A 65-year-old man walks into your general practice surgery and wants to discuss PSA-screening for prostate cancer. Even with the most recent prostate cancer screening guidelines on your desk, you wonder whether some approaches are more effective than others in communicating with patients about such evidence.*

Introduction

Making evidence-based decisions with patients requires a complex process of integrating evidence-based information with clinical findings, contextual factors and patient preferences (see Fig. 1) (Haynes *et al.* 2002). The respective role of each of these components will vary according to each clinical decision (Trevena & Barratt 2003).

Moral, ethical and legal imperatives require patients to be informed by high quality information (General Medical Council 1998) and instruments such as the DISCERN tool (Charnock *et al.* 1999) are useful for evaluating the quality of consumer information. However, even if consumer information is evidence-based and unbiased, what do we know about the evidence for the effective design of communication tools?

Epstein *et al.* (2004) published a framework for participatory decision making but despite the importance of this topic, there have not been any systematic reviews of the evidence for effective tools and effective formats for increasing patient understanding of evidence and eliciting patient preferences. In particular, there has not been a systematic compilation of the evidence from good quality randomized controlled trials (RCTs) and existing systematic reviews.

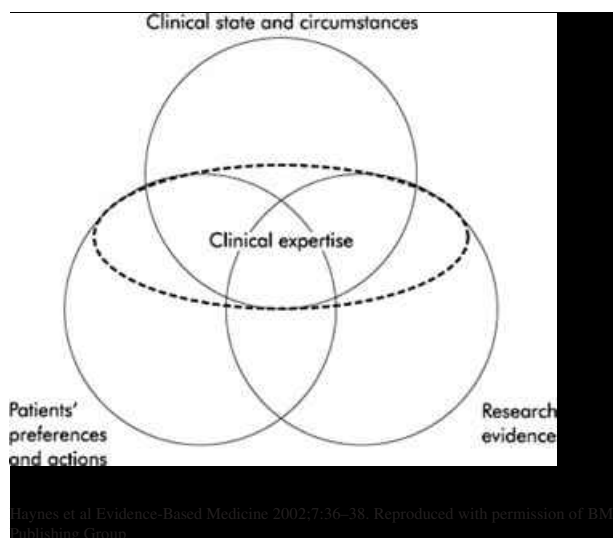


Figure 1 A Model for evidence-based decision making.

This paper reports on a systematic search of the literature for evidence of effective strategies for communicating with patients about evidence. It uses the prostate cancer screening scenario described above to illustrate how the results of this search might be put into practice.

Methods

We structured three explicit questions to address aspects of communicating with patients about evidence (Table 1).

This included the identification of interventions and outcomes of interest. The commonly accepted definitions of the communication tools are summarized in Fig. 2.

It was decided to include studies that were RCTs and systematic reviews of RCTs, and to exclude studies that did not address the question; were about patient education; were focused on skills and behaviour outcomes (such as increasing attendance at screening) without attempting to increase understanding or knowledge; were concerned with counselling as a therapeutic intervention (as opposed to a method of communicating evidence); or were specific to communication regarding clinical trial participation. For Question 1, we included studies that were identified as assessing change in knowledge, perception of risk, or informed consent either as a primary or secondary outcome.

The Cochrane Library, Medline, PsychInfo, Embase, CancerLit and authors' personal files were all searched up to and including June 2004 for each of the three questions using the search strategies outlined in Table 2. The grey literature and papers in a foreign language were not included.

After excluding studies outside the criteria, we were left with 46 RCTs and 11 systematic reviews on Question 1, 17 RCTs on Question 2 and 9 RCTs for Question 3 (Fig. 3).

We used the quality checklist from Glasziou and Irwig (Glasziou *et al.* 2001) to appraise the RCTs and the checklist from Guyatt *et al.* (Evidence-Based Medicine Working Group 2002) to appraise the systematic reviews. Of the 11 reviews found, 10 were of reasonable quality and were therefore included. There was substantial overlap between the trials included in the systematic reviews and those we had

Table 1 Questions about strategies for effective communication with patients

<i>Population/Problem (P)</i>	<i>Intervention/s (I)</i>	<i>Comparator/s (C)</i>	<i>Outcome/s (O)</i>
1. What are the most effective communication tools to improve patient understanding of 'evidence'?			
Patients making healthcare decisions	Decision aids Brochures/pamphlets/leaflets Videos Websites Tailored computer programs Verbal advice Structured counselling	No tool or other tools	Patient – Understanding – Knowledge – Comprehension
2. What are the most effective formats to represent probabilistic information to improve patient understanding of 'evidence'?			
Patients making healthcare decisions	Numeric Absolute risk Relative risk Graphical (Histograms/Pie charts/line graphs, 100 faces) Pictures/illustrations/diagrams Text words	No method or each other	Patient – Understanding – Knowledge – Comprehension
3. What are the most effective strategies to elicit patient preferences/beliefs/values relating to 'evidence'?			
Patients making healthcare decisions	Decision aids Decision analysis tools Touch screen computers Questionnaires – Question prompt sheets – Rating scales	No tool or other tools	Patient – Satisfaction with decision – Adherence to decision – Anxiety – Decisional Conflict – Involvement in decision-making

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Table 2 Search strategies**Question 1**

Communication OR decision support techniques OR pamphlets OR decision aid OR brochure OR video recording OR Internet OR patient education OR counselling OR advice OR tailored OR risk communication and comprehension OR understanding OR knowledge OR informed consent and meta-analysis OR randomized controlled trial

Question 2

Probability OR num\$ OR risk OR relative risk OR absolute risk OR framing OR data display OR graph OR picture OR text and communication AND(understanding OR comprehension OR knowledge and meta-analysis OR randomized controlled trial

Question 3

Preference OR belief OR value OR utility and decision aid OR decision support OR decision analysis OR rating scale OR question OR computer OR decisional conflict OR informed consent OR decision making OR patient education and informed consent OR decision making OR patient education OR adherence OR anxiety OR involvement and meta-analysis OR randomized controlled trial

identified independently. Duplicate publications, sub-analyses and trials already contained within these systematic reviews were excluded. We did however, validate our quality review process by cross-checking a subset of 12 excluded trials against quality assessments in the reviews. Agreement was 100%.

The remaining 48 RCTs not excluded on this basis were then appraised independently by two authors. Consultation was required for three studies and consensus about inclusion was reached. A grading system of A to C based on the Cochrane Reviewers' Handbook (Cochrane Collaboration 2003) was used

Tailored print information: Printed information provided on the basis of individual data characteristics. This data may be collected by a number of methods e.g. interview, computer, patient record systems etc.

Decision aids: "Interventions designed to help people make specific and deliberative choices among options (including status quo) by providing (at a minimum) information on the options and outcomes relevant to a person's health status. They may include a decision-making support framework or exercise that allows people to synthesise the evidence with their personal values and preferences (values clarification exercise)." (O'Connor *et al.* 2003)

Consultation summaries: Interventions offering videotape, audiotape recordings, written summaries of consultation or standardized verbal or written instructions

Provider training in a patient-centred approach: Training that promotes shared control of the clinical consultation and decisions about healthcare problems between the provider and patient. A focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts

Videos: Videotape-recorded information about healthcare. (Not providing options as would be the case with a decision aid)

Interactive touchscreen computer: Computerised information (not tailored or providing options as would be the case for a decision aid)

Evidence-based leaflets: Written information within a leaflet (not tailored or providing options or values clarification as would be the case for a decision aid).

Question prompts: A list of predetermined questions that the patient might use in a consultation.

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Figure 2 Definitions of communication tools used in this search.

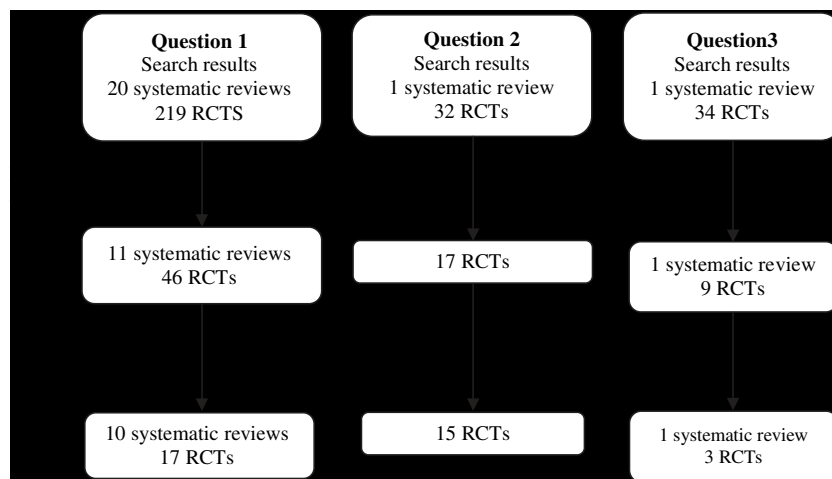


Figure 3 Flow chart of search and appraisal results.

to give each study an overall grade. All studies with a C grading were excluded. Many of the excluded RCTs did not report the method of randomization used or follow-up rates. Although blinding the outcome assessment in RCTs in this research area poses a particular challenge, this was achieved in some studies. Systematic reviewers found it difficult to pool effect sizes for many of the outcomes owing to heterogeneity of measures and lack of reported data.

Results

Question 1: effective tools for communicating with patients about evidence

After appraisal we included 10 systematic reviews (Walsh *et al.* 1998; Skinner *et al.* 1999; National Centre for Reviews and Dissemination 2000; Edwards *et al.* 2003; Lewin *et al.* 2001; O'Connor

et al. 2003; Scott *et al.* 2003a,b; Toelle & Ram 2004; Johnson *et al.* 2004) and 17 additional trials (Lewis *et al.* 1991; Agre *et al.* 1994; Hopper *et al.* 1994; O'Neill *et al.* 1996; Little *et al.* 1998; Paci *et al.* 1999; Graham *et al.* 2000; Lees & Rock 2000; Hewison *et al.* 2001; Newsham 2002; Cope *et al.* 2003; Gattellari & Ward 2003; Holloway *et al.* 2003; Montgomery *et al.* 2003; Volk *et al.* 2003; Whelan *et al.* 2003; Lichtman *et al.* 2004) about evaluating the effectiveness of various communication tools to increase patient understanding of evidence. The studies are grouped by intervention or type of communication tool in Table 3. In summary, this table indicates that the provision of information using most available communication tools is better than no communication tool for increasing knowledge about health care. In general, the more tailored and interactive the method of communicating evidence, the greater the resulting level of knowledge and understanding in patients (Edwards *et al.* 2003; O'Connor *et al.* 2003). None of the studies we found assessed whether it was more effective to give information before, during or after the consultation. In fact, the few studies that assessed strategies within the consultation were excluded for quality reasons, indicating that it is difficult to assess the effectiveness of such strategies. Training for health care providers in patient-centred approaches was also an effective strategy for increasing patient understanding of evidence.

Question 2: effective formats for communicating probabilistic information

After appraisal, we included 15 RCTs (Michielutte *et al.* 1992; Inglis & Farnill 1993; Gigerenzer & Hoffrage 1995; Delp & Jones 1996; O'Connor *et al.* 1996; Feldman-Stewart *et al.* 2000; Gurm & Litaker 2000; Marteau *et al.* 2000; Armstrong *et al.* 2001; Garrud *et al.* 2001; Hollands & Spence 2001; Man-Son-Hing *et al.* 2002; Christensen *et al.* 2003; Lee & Mehta 2003; Sheridan *et al.* 2003) that considered the effectiveness of different formats for communicating probabilistic information and found no systematic reviews of randomized trials (Table 4). It was found that for both written and verbal information, patients have a more accurate perception of risk if probabilistic information is presented as numbers rather than words (Marteau *et al.* 2000; Man-Son-Hing *et al.* 2002). One RCT

suggests that natural frequencies or event rates are better understood by most people than probability formats with varying denominators (Gigerenzer & Hoffrage 1995). Changes in risk are better understood if absolute risk reduction or relative reduction with baseline risk formats are used (Christensen *et al.* 2003; Sheridan *et al.* 2003). In some settings, detailed written risk information (including harms) increases knowledge and satisfaction without changing anxiety (Inglis & Farnill 1993; Garrud *et al.* 2001). Illustrations within narrative text compared with bullet point information can increase comprehension (Michielutte *et al.* 1992) and cartoons in one study increased understanding, adherence and recall in patients leaving emergency departments, compared with text only information (Delp & Jones 1996). This effect was greater in patients from low educational backgrounds. Patients can understand survival curves, when given more than one opportunity to do so (Armstrong *et al.* 2001). Framing information in terms of either benefits or harms can affect patient preferences (O'Connor 1989; Gurm & Litaker 2000). There is some evidence to suggest that vertical bar graphs with numeric estimates may be the best way to graphically represent probabilities (Feldman-Stewart *et al.* 2000; Hollands & Spence 2001).

Question 3: effective strategies for eliciting patient preferences

We found one systematic review (O'Connor *et al.* 2003) and three RCTs that considered interventions to elicit patient preferences (Soucek *et al.* 2000; Montgomery *et al.* 2003; Sheill *et al.* 2003). Based on the limited evidence available, decision aids and decision analysis appear to be effective tools for eliciting preferences (O'Connor *et al.* 2003). It appears that standard utility measures are useful and stable at a group level (Sheill *et al.* 2003). Standard gamble and time-trade-off methods (where patients weigh up one health state against another) were shown to be poorly predictive of preferences in men with prostate cancer (Soucek *et al.* 2000). However, preferences for an individual person vary and are better elicited by reflective values clarification exercises (Sheill *et al.* 2003). Thus utility measures may be more appropriate for policy level decision making and values clarification for clinical decision making.

Table 3 Communication tools effective in increasing patients' understanding of the evidence

<i>Type of communication tool</i>	<i>Level of evidence</i>	<i>Source of evidence</i>	<i>Results</i>
Tailored print information	Level I	Four systematic reviews (Skinner <i>et al.</i> 1999; National Centre for Reviews and Dissemination 2000; Edwards <i>et al.</i> 2003; Toelle & Ram 2004)	Results not pooled but tailored print communication was better remembered, read and perceived as relevant or credible compared with non-tailored information.
Decision aids (DA)	Level I	One systematic review (O'Connor <i>et al.</i> 2003) and three additional RCTs (Gattellari & Ward 2003; Montgomery <i>et al.</i> 2003; Whelan <i>et al.</i> 2003)	Greater knowledge of options (Weighted Mean Difference (WMD) = 19 out of 100, 95% CI: 13–25); more realistic expectations (RR = 1.48, 95% CI 1.02–2.14); lower decisional conflict (WMD = –9.0 of 100, 95% CI –15–3); reduction in number of people who were passive in decision making (RR = 0.6, 95% CI 0.5–0.8). Consistent trend for DAs to do no better than comparisons in affecting satisfaction with decision and decision making process, and anxiety. Effect on decision was variable. More interactive formats such as computerized, interactive versions appear to have a greater effect size compared with audio-booklets or booklets with summary.
Consultation summaries or instructions (audiotapes, written and verbal)	Level I	Two systematic reviews (Scott <i>et al.</i> 2003b; Johnson <i>et al.</i> 2004) and two additional RCTs (Paci <i>et al.</i> 1999; Cope <i>et al.</i> 2003)	83–96% of patients found summaries to be valuable. Results were not pooled but showed better recall of, and greater satisfaction with, information received. No studies found an effect on anxiety or depression. Standardized verbal instructions were better than non-standardised. There was no added benefit if a written copy of the standardized instructions was supplied in addition to standardized verbal instructions.
Provider training in a patient-centred approach +/-risk communication	Level I	Four systematic reviews (Lewin <i>et al.</i> 2001; Walsh <i>et al.</i> 1998; National Centre for Reviews and Dissemination 2000; Scott <i>et al.</i> 2003a) and two RCTs (Holloway <i>et al.</i> 2003; Lichtman <i>et al.</i> 2004)	Improved patient satisfaction, knowledge, perception and consultation processes. Not shown to effect behaviour.
Video	Level II	Five RCTs (Lewis <i>et al.</i> 1991; Agre <i>et al.</i> 1994; Lees & Rock 2000; Hewison <i>et al.</i> 2001; Volk <i>et al.</i> 2003)	Compared with usual practice, videos increased knowledge about options without affecting anxiety. They can also increase patient involvement in decision-making. This effect was particularly evident in low SES subgroups. One study compared verbal, written and video information formats and found no significant difference in knowledge between groups.
Interactive computer aids/touch screens, etc.	Level II	Three RCTs (Hopper <i>et al.</i> 1994; Graham <i>et al.</i> 2000; Montgomery <i>et al.</i> 2003)	Compared with audio-booklet or written information, interactive computer information increases knowledge, realistic expectations of outcomes, patient participation, and reduces decisional conflict. Patients preferred this format more than leaflets.

Table 3 *Continued*

<i>Type of communication tool</i>	<i>Level of evidence</i>	<i>Source of evidence</i>	<i>Results</i>
Evidence-based leaflets	Level II	Two RCTs (Newsham 2002; O'Neill <i>et al.</i> 1996)	Increased knowledge compared with no leaflet. Increased reported adherence to therapy in parents of children with amplyopia.
Question prompts	Level II	Two RCTs (Little <i>et al.</i> 1998; Paci <i>et al.</i> 1999)	Additional increase in knowledge if used in conjunction with a leaflet.

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Table 4 Strategies for the effective communication of probabilistic information

<i>Strategy</i>	<i>Level of Evidence</i>	<i>Source of evidence</i>	<i>Results</i>
Numeric representation of probabilities	Level II	Two RCTs (Marteau <i>et al.</i> 2000; Man-Son-Hing <i>et al.</i> 2002)	For both written and verbal information, patients have a more accurate perception of risk if probabilistic information is presented as numbers although some may not prefer them.
Probabilities expressed as natural frequencies (i.e. event rates)	Level II	One RCT (Gigerenzer & Hoffrage 1995)	Expressing probabilities as an event rate out of 100, 1000 or 10 000 is better understood by most people compared with a probability format.
Represent changes in risk in absolute terms or relative terms with baseline risk	Level II	Two RCTs (Christensen <i>et al.</i> 2003; Sheridan <i>et al.</i> 2003)	Absolute risk reduction or relative reduction with baseline risk information is better understood than number needed to treat and other formats.
Represent differences in proportions as vertical bar graphs	Level II	Two RCTs (Feldman-Stewart <i>et al.</i> 2000; Hollands & Spence 2001)	Although numerical information is the most accurate method of estimating differences in proportions, vertical bar graphs are the quickest and most accurate for discriminating general differences (compared with horizontal bars, pie charts, systematic and random ovals).
Balanced information about benefits and harms	Level I, II	Two RCTs (Inglis & Farnill 1993; Garrud <i>et al.</i> 2001)	In some settings, detailed written risk information (including harms) increases knowledge and satisfaction without changing anxiety.
Use of illustrations and/or cartoons	Level II	Two RCTs (Michielutte <i>et al.</i> 1992; Delp & Jones 1996)	Illustrations (particularly cartoons in one study) increased understanding, adherence and recall in patients leaving emergency departments compared with text only information. There was a greater effect in patients from low educational backgrounds.
Survival curves	Level II	One RCT (Armstrong <i>et al.</i> 2001)	Patients can understand survival curves, when given more than one opportunity to do so.
Framing information as harms or benefits	Level II	One RCTs (O'Connor 1989; Gurm & Litaker 2000)	Framing of information in terms of either benefits or harms can affect patient preferences.

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Discussion

Communicating with patients about evidence

This systematic review has highlighted that communicating with patients about evidence does increase their understanding regardless of the tools used. There appears to be a greater effect if information is structured (either written, verbal or video) or interactive (computer, touch screen, question prompts) and particularly if the information is tailored to the individual. There is an emerging evidence-base about effective ways of communicating probabilities, a common requirement when discussing evidence with patients. Numeric values, expressed as event rates in groups with and without the intervention being considered (also called natural frequency formats) should be used where possible. Written information can be more effective if illustrations and graphs are used. There is still much to be learnt about effective strategies for eliciting patient preferences, although values clarification exercises rather than standard utility techniques appear to be more appropriate for individual decision making.

One of the difficulties in generalizing from this literature, is that trials have been conducted in a wide variety of clinical settings using a range of clinical problems and outcome measures. In this review therefore it was not possible to pool outcomes and no statistical test of heterogeneity was performed. Nevertheless, the consistency of the direction of effects across a range of settings increases the likely generalizability and the validity of our findings.

Finding evidence-based communication tools about PSA screening for prostate cancer

If we return to our original scenario about the patient wanting to discuss the pros and cons of prostatic specific antigen (PSA) testing we might consider how the results of this systematic review could be applied. It seems that decision aids are potentially useful tools for communicating the pros and cons of particular health decisions and for eliciting patient preferences. An inventory of patient decision aids is available in the Cochrane Library (O'Connor *et al.* 2003). There have been a number of prostate screening decision aids evaluated by RCT and published (Flood *et al.*

1996; Davison *et al.* 1999; Volk *et al.* 1999; Schapira & VanRuiswyk 2000; Gattellari & Ward 2003), but many of these are not readily accessible for busy clinicians or interested consumers.

The NHS Cancer Research UK Primary Care Education research group has produced an information pack for Prostate Cancer Risk Management. These are available to UK practitioners from the Department of Health Response line. Tear-off sheets listing the pros and cons of PSA testing are contained within this pack as a useful resource. These are available at the URL (<http://www.cancerscreening.nhs.uk/prostate/prostate-patient-info-sheet.pdf>). In addition we found some patient experiences of PSA testing on DIPEX (<http://www.dipex.org>). However, finding these resources required some prior knowledge on our part and considerable time. It is of concern that consumers using common search engines on the Internet are very likely to access information that does not apply the results of our review on effective strategies for communicating with patients about evidence.

Summary

Applying evidence effectively in practice involves synthesizing research evidence with clinical findings and patient preferences, beliefs and values. There is good evidence that a range of communication tools can increase patient understanding and knowledge in health care decision making. There is also an emerging body of evidence about how to communicate probabilistic information to patients and elicit their preferences for making a clinical decision. While more research is needed on effective methods for communicating information and improving patient knowledge and understanding of information, work also needs to be done on effective ways for providing access for clinicians and consumers to such findings and tools. Where this is not possible, structured verbal or written information is an effective tool.

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