

**How to prepare and present
evidence-based information for
consumers of health services:
A Literature review (1999)**

NHMRC

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1 Objective

To identify the best evidence about how to prepare and present evidence-based information to consumers of health services to assist them with decision making.

2 Overview

The papers identified for this review described research within three major themes; the information needs and preferences of consumers, evaluations of information materials for consumers, and the process of developing information materials. Consequently this review is divided into three sections based on these themes:

- **Needs assessment and preferences for information presentation**

The most important source of information for this review must be consumers. Therefore, the first section focuses on the needs, preferences and abilities of consumers.

- **Evaluation studies of different presentations of information for consumers**

The second part of the review covers the experimental evidence, ie which information packages/presentation format and decision support packages have been shown to be effective in helping consumers to make satisfying decisions and to achieve better outcomes.

- **The process of developing information for consumers**

The review closes with a third section briefly summarising the work of the leading developers of information and decision support packages for consumers around the world. This section outlines the current evidence-based approaches to the process of developing consumer information and decision support materials.

Clearly these themes are interconnected; both the needs and preferences of consumers and existing knowledge about what types of information presentations are most useful to consumers must feed into an effective process of developing new materials. As new materials are developed they should be evaluated and the results of the evaluations can then inform the development of future materials (Figure 1).

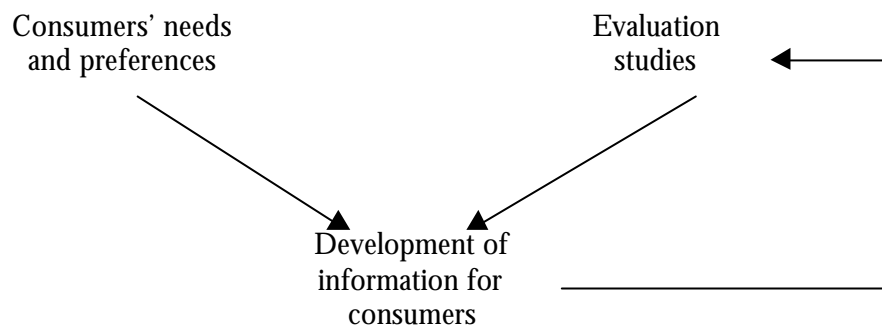


Figure 1 Developing information for consumers

3 Methodological note

This is a piece of commissioned research which reviews the evidence about what is effective in presenting evidence-based information to consumers of health services. It is not, and was not commissioned to be, a systematic review of the topic. A systematic review of the entire area would be so extensive as to be virtually impossible. Systematic reviews of some components of this topic are currently being developed and undertaken by the Cochrane Collaboration's Consumers and Communication Review Group. We advise readers interested in this field to access the Cochrane Collaboration websites in order to obtain these reviews as they are published.

The literature on this topic is diverse and diffuse and is not readily amenable to systematic review. We have undertaken a limited literature review, concentrating on recent research (since 1990) as this is the timeframe for the development of the evidence-based health care movement. We have concentrated on major computerised databases for computer searching (Cochrane, Best Evidence, Medline and EMBASE). These searches were supplemented with review of reference lists and some Internet searching. Where possible we sought Australian data, and have drawn on the work of a number of Australian organisations including the National Health and Medical Research Council, the National Breast Cancer Centre, the Australian Bureau of Statistics and local expertise such as local departments of health and local universities. Advice has also been sought from international colleagues, particularly those involved in the work of the Cochrane Consumers and Communication Review Group. Our search therefore has been a sensitive one which located many hundreds of references some of which had to be discarded on the basis of titles and, where available, abstracts, in order to make this project practical.

The only exception to this approach is the section of the review which deals with randomised controlled trials of decision support packages/decision aids to help consumers with clinical decision making. A systematic review of this area was done because consumers are increasingly being asked to participate in clinical decision making and aids to support this process are going to be widely needed. In addition, this particular area has been evaluated by randomised trial designs and has shown such promise that the further development and evaluation of such packages seems inevitable. Decision aids also have the advantage of being able to use multi-media presentations (eg video, computer packages) which will increasingly be available on the Internet. For this section, it is likely that all the relevant trials have been located and included. All the trials have been appraised according to standard critical appraisal criteria and their methods and results summarised. The materials developed and evaluated by the best trials have been obtained from the developers (in the United States and Canada) and these examples have guided the step-by-step guide developed for this project.

In the remainder of the review, we have attempted to review and summarise the main research findings in this area over the past decade. While it is unlikely that important themes have been omitted, any further papers which are identified as relevant and important will be incorporated into the final version of the review.

Finally, this is an expanding and rapidly changing field and this review will need regular updating to remain current.

4 Criteria for considering studies for this review

4.1 Participants

Studies should be based on consumers of health services (rather than clinicians, policy makers, health service administrators).

4.2 Studies

Studies should either be evidence-based themselves (ie, based on empirical data) or discuss the use of evidence-based information as the basis of information for consumers.

Identified studies fell into three categories:

1. Needs assessment and preference studies (how do people prefer information presented?)
2. Evaluation studies (how well do existing materials work in informing consumers and in assisting decision making?)
3. Process studies (reports/guides on how to make your own information materials for consumers with no evaluation component).

4.3 Study design

For category 1 studies, cross-sectional study design is appropriate and adequate. All studies that were relevant and included original data were included in the review.

For category 2 studies, a hierarchy of study designs exists with randomised controlled trials (and systematic reviews of randomised trials) providing the highest quality of evidence. All systematic reviews and randomised trials found were included in this review. Randomised trials of decision support aids and packages were critically appraised using standard criteria for assessing the validity of randomised trials.¹

For category 3 studies, evidence-based guides provide better quality examples than materials developed on the basis of opinions.

4.4 Outcomes

For evaluation studies, outcomes were broadly classified as short term (process), intermediate (impact) and long term (outcome) as follows:

- *process* — for example, readability, clarity, attractiveness of presentation;
- *impact* — for example, consumer satisfaction, level of comfort with decision making;
- *outcome* — for example, improved quality of life, reduced morbidity and mortality.

4.5 Timeframe

Studies published since 1990 were selected because our focus is on the presentation of evidence-based information for consumers. The evidence-based medicine movement largely dates from around 1990 and it is only since then that efforts have been made to develop and evaluate evidence-based materials for consumers. Our purpose is also to

investigate how to present information which facilitates consumer involvement in shared clinical decision making and again this is a recent development within health care.

5 Literature searching strategies and critical appraisal methods

Computerised searching was done in the following databases:

- Best Evidence
- Medline
- Embase
- Cochrane Database of Systematic Reviews

Searching was based on the following search terms:

consumer\$
patients
guidelines &
health education
patient education

writing
education
pamphlet\$
information

advocacy
participation
decision making
shared & decision\$
informed consent

Terms were generally searched separately and the resulting reference lists scanned for relevant articles (based on title and abstract) to make the search as sensitive as possible.

5.1 Author searches

We searched for other publications by authors of relevant, high quality papers. The authors we identified for this search were:

- Bastian H, Cochrane Consumers and Communication Review Group
- Coulter A, Kings Fund, London UK
- Entwistle V, Health Services Research Unit, Aberdeen, Scotland
- O'Connor A, University of Ottawa, Canada.

5.2 Internet

An Internet search was done using the following search terms:

consumer information
consumer education.

5.3 Kings Fund

We contacted the Kings Fund website and obtained their catalogue and library reference list which we searched for relevant publications. In addition we obtained their document 'Informing patients. An assessment of the quality of patient information materials'.

5.4 Cochrane Consumers and Communication Review Group

We contacted this group and asked them to provide relevant reading lists and references and also asked them for the names of prominent authors in this field.

5.5 National Breast Cancer Centre

Reviews and reports on relevant topics and consumer guidelines and documents were requested and provided.

5.6 Hand searching

We hand searched the reference lists of key papers, reviews and reports.

5.7 Networking

The following people were contacted and asked to forward relevant publications:

- Dr Phyllis Butow, Dept Psychological Medicine, University of Sydney
- Ms Paola Rio, Co-ordinator Cochrane Consumers and Communication Review Group
- Dr Annette O'Connor, School of Nursing, University of Ottawa
- Dr Andrew Wolf, Assistant Professor of Medicine, University of Virginia
- Foundation for Informed Medical Decision Making, Massachusetts General Hospital and Dartmouth Medical School
- Ms Sue Carrick, Consultant, National Breast Cancer Centre
- Ms Tracy Williams, Anti-Cancer Council of Victoria, PhD student at Deakin University, PhD topic: Risk perception and risk communication in breast cancer.

6 Review

6.1 Needs assessment and preferences for information presentation

To describe people's needs and preferences for information requires cross-sectional, descriptive studies. The study samples should be representative of the population from which they are drawn and the methods of assessing people's needs and preferences should be valid and reliable.

6.1.1 Information needs

Consumers' preferences for information have been explored in detail.^{2 3 4} In three cross-sectional surveys (two in Canada and one in the UK) Degner et al asked three groups of patients (breast cancer, benign breast disease and prostate cancer) to rank their

information needs. In each study the findings were consistent, as illustrated in Table 1 below:

Table 1 Information needs identified by consumers

High priority need	Medium priority need	Low priority need
Chances of cure	Self-care at home	Effect on sexuality
Spread of disease	Impact on family	
Treatment options	Social activities	
Family risk		

The same high priority needs were identified by people who were newly diagnosed and by those who had been diagnosed six months or more previously. People who were further from time of diagnosis (six months or more) rated information about self-care at home more highly. Younger women (<50 years) rated sexuality highly and older women (>70 years) rated self-care at home highly. These information needs are generally similar to those found by Tetzlaff⁵ who also explored preferred sources of information (see Sources of information, section 6.1.4).

In a recent series of focus groups with consumers, Coulter et al (of the Kings Fund)⁶ identified consumers' information needs as being information to:

- understand what is wrong
- gain a realistic idea of prognosis
- make the most of consultations
- understand the processes and likely outcomes of possible tests and treatments
- assist in self-care
- learn about available services and sources of help
- provide reassurance and help to cope
- help others to understand
- legitimise seeking help and their concerns
- learn how to prevent further illness
- identify further information and self-help groups
- identify the 'best' health care providers.

People particularly need to hear how others dealt with similar situations, and there is evidence that consumers value highly presentations of other people's descriptions of their symptoms, their treatment and side effects and how they coped with their illness.⁷

Information needs may be different for minority groups, defined by, for example, socio-economic status, cultural or religious characteristics. Only one paper was identified which attempted to design materials especially for such a minority group (economically disadvantaged African Americans).⁸ Developing materials in a range of languages and using language and presentations which are culturally acceptable is obviously important and will increase the complexity of the task of developing consumer information. However, the same principles are likely to apply, that is, it will be important to identify the needs and preferences of the consumers who will use the information, involve them in the process of development and then evaluate the materials.

Recommendations

Information for consumers should include information about cure rates, spread of disease (where relevant), treatment options and family risk (where relevant) as there appears to be consistent demand for this information.

It may be practical to assess individual consumers' needs for information and provide appropriate information when required.

Information from other consumers about how they felt and how they coped with investigations and different treatment options is likely to be helpful.

Decisional role preferences

In the same series of studies Degner et al asked patients about the role they prefer in clinical decision making. Using five cards with illustrative cartoons they asked patients to rank their preferred decision making relationship with a clinician from passive ('I prefer to leave all decisions regarding treatment to my doctor'), through collaborative ('I prefer that my doctor and I share responsibility for deciding which treatment is best for me') to active ('I prefer to make the decision about which treatment I will receive').

In their first study (conducted in 1988) with general cancer patients and community controls,⁹ 59% of the patients preferred a passive role, 29% a collaborative role and 12% an active role. Among the community controls (who did not have disease) 64% said they would want an active role if they developed cancer.

Age was the most important predictor of decision-making preference with younger people preferring an active role. Women and well educated people also tended to prefer a more active role, but these three variables only explained 15% of the variance in patient role preferences. The more recent studies with breast and prostate cancer patients found similar results, although women with breast cancer were more likely to choose an active role; in their largest study (of 1012 women with breast cancer) conducted in 1992–1994, 22% of women wanted to select their own treatment, 44% wanted to select treatment collaboratively with their physicians and 34% wanted to delegate the responsibility to their physicians. Only 42% of women believed they had achieved their preferred level of control in decision making. Among women who preferred an active role, only 20% felt they had achieved that role and among those who preferred a passive role, a small number felt they had been pushed into a more active role. In a similar but smaller study of 57 men with prostate cancer, the majority of men (58%) preferred a passive role, 23% a collaborative role and 19% an active role.

In general the methodology of these studies is good; data are provided on sample selection and response rates (which were around 75%–85%). Measurement has been carefully conducted with instruments which have been assessed for reliability and validity. None of these studies provided confidence intervals, but the raw data are given; for the study of 1012 women, the 95% confidence limits will be quite narrow (about $\pm 2\%$). It seems likely these data are both valid and reasonably precise. It is difficult to assess whether the results could be applied to Australian consumers although there do not appear to be any compelling reasons not to apply the findings here.

Qualitative work by Degner et al with a small group ($N=35$) of women with breast cancer explored the relationship between decision making preferences and information needs. This study¹⁰ found that patients who preferred an active role in decision making preferred detailed (preferably written or audiotaped) information about their diagnosis and all major

treatment options compared to patients who preferred a passive role. Patients who preferred a passive role simply wanted information about the single best treatment. All patients wanted detailed information about side effects associated with treatment. The differences in information and decision making preferences may be related to people's coping styles. For example, some patients will seek information as a coping response to a threatening illness, while others will actively avoid information, preferring distraction as a coping response.¹¹

The work of Degner et al is consistent with other work. For example, an Australian study conducted in Newcastle with 511 health professionals and 152 patients explored opinions on decision making about cardiopulmonary resuscitation (CPR) at the end of life.¹² Eighty per cent (95% CI 72 to 86%) of patients and 99% (95% CI 98 to 100%) of health care professionals thought patients' views should be taken into account, and 29% (95% CI 22 to 38%) of patients and 14% (95% CI 11 to 17%) of health care professionals indicated that doctors should be the main decision makers.

An American study addressed decision making about invasive procedures and found that of 467 male patients (mean age 65 years) 68% preferred shared decision making, 21% preferred physician-based decision making and 11% preferred patient-based decision making.¹³

However, timing is probably also important and information needs and preferences for involvement in decision making may not be stable over time. General preferences for information appear to be relatively stable but preferences for specific topics may vary with time.¹⁴ For example, patients whose condition has recently worsened are more likely to want less involvement in decision making. Butow et al also report that recall of information is very poor for information given at the time of a serious diagnosis or initial consultation.¹⁵ It may be inappropriate to provide information at the time of diagnosis; a better strategy may be to provide information in small increments that allow the consumer time to adjust to the diagnosis and need for treatment decisions.

Shared decision making

Shared decision making is increasingly advocated as the best approach to clinical decision making.^{16 17} In shared decision making the physician and the consumer (at least, there may be other participants, eg, the patient's family) are involved, share information and finally agree on the treatment approach.¹⁸ The move towards shared decision making has major implications and consequences for how information is presented to patients. Evaluation studies are now available on a range of (shared) decision support methods and these are reviewed under Evaluation studies (section 6.2).

Recommendations

Decisional role preferences vary between people and may vary over time. Most people prefer a collaborative approach to decision making but a substantial minority prefer an active (patient-based) role or a passive (physician-based) role. People who prefer active or collaborative roles need more detailed information especially about major diagnostic and treatment alternatives.

It may be useful to assess individual preferences and to provide differing information depending on whether the patient's preference is for an active, collaborative or passive role.

6.1.2 Framing effects

The 'framing literature' dates back at least to the early 1980s. Although this review retrieved papers published after 1990, it seems appropriate to summarise the earlier key findings here. Much of the literature around how information is framed has focused on whether a positive or negative frame is used. For example, McNeil et al found that patients, students and physicians were more likely to prefer treatment options for which outcomes were framed as the probability of survival rather than as the probability of dying.¹⁹ Many others found similar results^{20 21} — for example Tversky and Kahneman found that people's preferences (in relation to monetary outcomes and loss of human life) are often reversed depending on how the information is framed and that their choices are frequently irrational.²² It is now accepted that patient choices can be influenced by positive or negative framing.

Other work has shown that framing probability information in numbers is more reliable than using verbal descriptions. Descriptors such as 'very unusual', 'infrequent', 'atypical', 'characteristic', 'vast majority', and 'invariably' are 'translated' into very different numerical estimates by different people.²³ For example the verbal label 'occasionally' was described as meaning anywhere between 3% and 40% of events in a study of 103 physicians and 106 non-physician participants. Even among the physicians (who commonly use these verbal descriptors to describe frequencies of events) agreement about the numerical value of the descriptors was very poor.

One aspect of framing which is very important to decision making but which has only been addressed recently, is the presentation of numerical data about treatment effects. Reductions in risk (that is, the benefits of treatment) may be summarised in several ways. The most commonly used is relative risk reduction, which is based on the ratio of the risk in a treated group to the risk in an untreated group. The most commonly used alternative expression is 'absolute risk reduction', which is the difference in risk between a treated and an untreated group. For example, if a treatment reduces the risk of death from coronary artery disease within a year from 10 per hundred in the control group to 5 per hundred in the treatment group, the relative risk reduction is 50%.ⁱ The absolute risk reduction is $10/100 - 5/100$ or 5%. Thus the percentage generated by using the relative risk reduction (50%) is far more impressive than the percentage generated by the absolute risk reduction (5%). However, the absolute risk reduction conveys much more meaningful information and is easy to understand. For example it can simply be expressed as 'the treatment reduces the risk of death from coronary artery disease from 10 per 100 to 5 per 100'. This is more meaningful than simply saying 'Your risk of death is halved by taking this treatment', because in the latter statement there is no information about how likely one is to die without treatment. Use of the relative risk reduction can greatly magnify the apparent effectiveness of treatment, especially when the underlying risk of the event is low, and can thus influence decision making.

Malenka et al explored the effect of presenting information as relative or absolute risk reductions with 470 patients in a general medicine outpatient clinic in northeast America.²⁴ Patients were asked hypothetical questions about which drug they would prefer to be treated with for hypertension; the drugs were in reality equally effective but their effectiveness was presented as a relative risk reduction and as an absolute risk

ⁱ This is calculated as Relative Risk = Rate in the treated group/rate in the control group, which is equal to $5/100$ divided by $10/100$ or 0.5. The Relative Risk Reduction is $[1-0.5] \times 100$ which is 50%. This is equivalent to saying those in the treated group have half the risk of dying from coronary artery disease as those in the control group.

reduction. Only 15% of patients recognised that both drugs were equally effective and therefore did not mind which drug they received. 57% of patients preferred the drug which was described in terms of its relative risk reduction, 15% the drug described in terms of its absolute risk reduction and 13% were unable to decide.

This study further asked people to calculate the absolute risk reduction from a treatment, given the relative risk reduction and the underlying risk of the outcome. Twenty-eight per cent of patients were able to do this correctly, about 50% calculated incorrect responses and about 20% were unable to answer.

The findings are striking because they clearly illustrate the preference for treatment options presented as relative risk reductions and underscore that many people do not have the numeric skills to manipulate risk data correctly. In this study those with education past grade 13 were twice as likely as those with less education to be able to convert relative to absolute risk and men were more likely to be able to do it than women. Nevertheless subjects with the higher category of education were *more likely* to prefer the medication with the benefit expressed in relative terms.

Similar results were obtained by Hux and Naylor in their cross-sectional study of 100 outpatients in Canada.²⁵ Subjects were asked to make a Yes or No decision about taking what were implied to be three different lipid lowering drugs which, in fact, were three different ways of presenting the efficacy data of the same drug. When advised of a relative risk reduction ('34% reduction in heart attacks') 88% assented to treatment. Forty-four per cent assented to treatment by the drug described by the absolute risk reduction of '1.4% fewer patients had attacks' and 31% assented to treatment when the data were presented as a number needed to treat ('treat 71 persons for 5 years to prevent one heart attack'). Of the 100 patients, 7% said No to all three drugs and 21% reported they would take each of the drugs if their physician recommended it (all drugs were said to have no side effects and subjects were told to assume the cost of medication would be covered by insurance).

Similar studies have been done with clinicians,^{26 27} other health professionals²⁸ and policy makers.²⁹ All have shown that the format of presentation affects decision making, with people being more likely to favour treatments for which effects are presented as relative risk reductions.

Recommendation

Care should be taken to present information in terms of absolute risk reductions instead of, or as well as, relative risk reductions.

The best method may be to express treatment effects as the outcome rates in both treated and untreated groups.

6.1.3 Patients' abilities

Literacy

Consumers need information to make choices but their decision making may be impaired if they are unable to read and understand written materials.

Literacy is often assessed as a function of reading age or reading grade. Unfortunately, there is no simple, reliable relationship between the numbers of years of schooling and the grade level at which people can read. It has been estimated there is up to a four year

gap between years of school attendance and reading grade level.³⁰ Thus it is not possible to assume that someone with 12 years of schooling can read at grade 12 level. Nevertheless, as these measures are commonly used, a table showing the relationship between school grade and reading age is provided below:

Table 2 School grade and estimated reading ages

Grade	K	1	2	3	4	5	6	7	8	9	10	11	12	13
Age	5	6	7	8	9	10	11	12	13	14	15	16	17	18

[from Ley P. *Psychology Health and Medicine* 1998;3:19–53]

To explore patients' ability to understand health information, Estey et al examined the reading and comprehension levels of 189 patients attending three university affiliated teaching hospitals in Canada.³¹ The average age of the group was 51 years and 53% were male. The average reported educational level attained was grade 8. On reading tests (WRAT-R) the average level attained was grade 7. Comprehension was tested on health information prepared to (a) grade 5 and (b) grade 9 level. On the grade 9 materials, 30% were able to comprehend the material independently, 31% with some help and 39% were not able to comprehend the information. The comparable percentages for grade 5 materials were 77%, 8% and 14%.

The results underscore the fact that many patients do not have sufficient reading and comprehension skills to understand written health information. The authors note that comprehension may be further reduced by anxiety about the illness, pain, drowsiness from medications, noisy wards and constant interruptions. Worse, these results probably overestimate literacy skills because those with poor skills were probably more likely to decline to participate in the study (no data were available on either the number or characteristics of those who declined to participate).

Larson assessed 100 randomly selected patients attending a Veterans clinic (age range 29–87 years, median 58 years) using the WRAT-R2 (Jastak Wide Range Achievement Test, revised level 2) standard reading test and found that 51% had a reading grade of grade 9 or less.³² This was despite the fact that only 36% had attended school to grade 9 or less and is typical of studies which have found that the reading grade is often 2–4 years lower than the number of years of school attended. Data from Larson's study are summarised below:

Table 3 Reading grades achieved by United States veterans

Reading grade	% of population estimated to read at this level	Cumulative %
0–3	12	12
4–5	19	31
7–9	20	50
10–12	24	74
>12	25	90

Assuming these data are generalisable, we can expect about 50% of people will only be able to read materials written at grade 9 or less, 30% will only be able to read materials written at grade 5 or less, and about 10% will only be able to read materials written at

grade 3 or less. This is consistent with other US research showing that about 40% of the adult population can only read at or below 8th grade level.^{33 34}

No directly comparable data are available for the Australian population, but it seems likely that Australians would have similar literacy problems. Reading grade data are not available from the census data collected by Australian Bureau of Statistics (ABS) and only limited data are available on the proportion of people who complete various school grades.ⁱⁱ However, in a study designed specifically to measure literacy in Australia conducted in 1996, ABS collected data on reading skills and classified the population into five broad bands of reading ability (Table 4).³⁵

Thus almost half the Australian population is likely to have some or considerable difficulty with written information materials. Materials for these groups will need to be developed so they are understandable for people with low literacy skills. Some limited advice about developing materials for low literacy populations is available.^{36 37}

Table 4 Percentage of Australian adult population in Levels 1–5 of literacy skill

Level 1	Very poor literacy skills with considerable difficulty using printed materials encountered in daily life.	19.7%
Level 2	Some difficulty in using printed materials encountered in daily life.	27.5%
Level 3	Able to cope with a range of printed materials but not able to use all materials encountered in daily life proficiently.	35.3%
Level 4	Good literacy skills — able to match and integrate information and perform arithmetic operations.	15.5%
Level 5	Very good literacy skills — able to use complex displays of information, use conditional information and perform multiple operations sequentially.	2.0%

Recommendation

Materials need to be developed at varying levels of literacy skill to reflect the diversity of literacy skills among consumers.

Numeracy

Quantitative information about benefits and risks may only be useful to patients who have some proficiency with probability and numerical concepts. To explore patients' numeracy skills and to assess whether patients can make use of risk reduction expressions, Schwartz et al conducted a study with 500 women (median age 68 years) in New England.³⁸ Women were selected at random from a registry maintained by the

ⁱⁱ Department of Education, Training and Youth Affairs data for 1997 show that 97% of students completed Year 10, 84% completed Year 11 and 72% completed Year 12 schooling.

Department of Veterans Affairs Medical Centre (response rate 64%). Numeracy was assessed by the following three questions:

'Imagine that we flip a fair coin 1000 times. What is your best guess about how many times the coin would come up heads in 1000 flips?' [... Times out of 1000].

'In the BIG BUCKS LOTTERY, the chance of winning a \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 1000 people each buy a single ticket to BIG BUCKS?' [... Persons out of 1000].

'In ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1000. What per cent of tickets to ACME PUBLISHING SWEEPSTAKES win a car?' [...%].

They assessed the extent to which women could manipulate risk data. This was done by allocating the women randomly to one of four groups which received information containing: (1) relative risk reduction and baseline risk; (2) relative risk reduction without baseline risk; (3) absolute risk reduction with baseline risk; (4) absolute risk reduction without baseline risk and asking the questions: 'How many women will die from breast cancer without mammography?' and 'How many women will die with mammography?'

In the assessment of numeracy, 30% of respondents had no correct answers, 28% had one correct answer, 26% had two correct answers and 16% had three correct answers.

Accuracy in applying risk reduction information was poor. Accurate responses were received from 17%, 10%, 33% and 7% of groups 1–4 respectively; therefore the group that performed best was the group given both absolute risk reduction and baseline risk data. Inaccurate responses tended to be in the direction of over-estimating the effectiveness of mammography. After adjustment for age, income, level of education and framing of the information, women with higher numeracy scores were more likely to be accurate in manipulating the data. Compared to a numeracy score of 0 correct responses, the odds ratios for accuracy were 1.3 (95% CI 0.3 to 4.7), 7.1 (95% CI 2.2 to 23.4), and 13 (95% CI 3.6 to 48.0) for numeracy scores of 1, 2, and 3 respectively.

Black et al assessed numeracy skills with 145 women aged between 40 and 50 years who were registered with the Dartmouth-Hitchcock Medical Centre.³⁹ The study group potentially comprised 787 women in the age group who were registered and who did not have breast cancer. Of these, 200 were selected at random to be invited to the study; completed questionnaires were received from 145 (73%) of the women. The median age was 44 years and 28% had a post-graduate degree. Numeracy was assessed by a question on probability (number of times a fair coin would come up heads in 1000 flips) and responses to questions on probability of developing and dying of breast cancer over the coming 10 or 20 years. Respondents were considered numerate if they correctly answered the first question and their answers to the remaining questions demonstrated awareness that the chances of developing breast cancer were equal to or greater than the chances of death from breast cancer. Using this criterion, 62% of the group was considered numerate. Each woman was also asked to estimate her probabilities of developing and dying of breast cancer in the next 10 years, with and without mammographic screening. From information provided on risk factors, each woman's actual risk of dying of breast cancer was estimated. Women over-estimated their probability of dying of breast cancer within 10 years by more than 20-fold. Assuming a 10% relative risk reduction from screening, respondents over-estimated the relative risk reduction by sixfold and the absolute risk reduction by more than 100-fold. Over-estimation was less extreme among the numerate group.

Recommendation

Numeracy skills in the population are likely to be generally poor, and probably contribute to over-estimation of both personal risks and effectiveness of treatments.

Health information materials need to take account of the fact that many people have poor numeracy skills and most people are unlikely to be adept at manipulating risk reduction information.

The best presentation of numeric data will include both absolute risk reduction and baseline risk information.

6.1.4 Sources of information

To explore whether computer access to information, help and support might help meet the needs of people living with or caring for people with chronic disease, Tetzlaff sent questionnaires to 120 families of children with cancer in remission (response rate 52%). Parents generally preferred to get information from medical staff but expressed reluctance to impose on the time of their medical provider. Other sources of information were nursing staff, books, other parents, support groups, newsletters and pamphlets. Live interaction was the most preferred means of getting information, but indirect media such as video was preferred to more traditional presentations such as text. Seventy per cent of parents reported being comfortable with computers and over 90% said they were useful and reasonably easy to learn to use.

[This study also found that 97% said they 'wanted to know everything they could about the disease', but at the same time 31% did not 'want to hear about the bad things'. They were most interested in the disease and its treatment, short and long term side effects and ways to cope. These interests changed with time; parents with recently diagnosed children wanted information on treatment, from 6 weeks to 6 months parents wanted to know how other people coped and after a year the primary concern was with long term side effects of treatment.]

After collecting the needs assessment data, Tetzlaff and colleagues worked with TJ Watson IBM Research Center to design a prototype multi-media workstation to respond to the information needs of families with children with cancer. The workstation was pilot tested with six families attending the Paediatric/Haematology/Oncology clinic at a major teaching hospital in New York. The parents were 'a little tentative' but the children were 'fearless' and enjoyed poking the touch sensitive screen. Parents were generally enthusiastic about access to such a system at home.

Video presentations also have the advantage of being able to provide vicarious experience through video clips of other people describing their experiences of symptoms, treatments and side effects. Such qualitative information is important because consumers often have to make decisions about treatments and outcomes that are outside their own experience. The Benign Prostatic Hypertrophy Shared Decision Making Program, for example, includes video interviews of patients describing their symptoms (such as acute urinary retention, sexual dysfunction and incontinence) before and after prostatectomy to help people decide whether to have surgery.⁴⁰

The Internet, interactive computer packages and video presentations all lend themselves to the provision of qualitative information about how people feel about their illness, how they experienced symptoms, how they coped and practical tips and advice. This

information can be provided in written form but is more compelling either 'live' or on film and provides very relevant and important information for consumers.

Thus it seems reasonable to suggest:

- consumers' questions and concerns generally go beyond what is available in printed educational materials
- computers are favourably regarded as a technology for addressing consumers' needs in the home
- computer based information can be both broad and deep to allow people to choose how much detail they want. Information can be layered — eg by hypertext links — so that information needed early, often or in emergencies is easily accessible while detailed or threatening information can be hidden to prevent inadvertent access or intrusive exposure.

Recommendation

Verbal communication with health professionals remains the preferred method of information exchange, but computers, videos and interactive multimedia technologies may also assist with consumers' needs for information. Computers, videos and interactive multimedia technologies may meet information needs better than traditional written information materials.

Access to the Internet in Australia

According to the latest data published by the Australian Bureau of Statistics, as of August 1998, 18% of all Australian households had access to the Internet from home.⁴¹ This is 46% greater than that recorded in February 1998. More than 4.2 million adults (23% of the total adult population) accessed the Internet in the 12 months prior to August 1998. The Internet is accessed most commonly at work, home, a friend or neighbour's house, TAFE or tertiary institution and public libraries.

Recommendation

About 20% of Australian homes have Internet access and this figure is increasing rapidly. Provision of health services information via the Internet and other multi-media seems to be acceptable and will probably have a major role in the future.

It seems appropriate to conclude this section by reference to an Australian study which assessed consumers' information needs, decision role preferences, preferences for numerical expressions of risk and preferences for emotional support and information sources.⁴² This study was conducted with 100 women with early stage breast cancer about their experience of being given verbal information about their prognosis. While this is a specific content area, it seems likely the findings are far more generally applicable. They found that:

- almost all women wanted information on the probability of cure (with and without treatment) and 10-year survival data

- 74% of women did not understand the statistical language used to present survival data
- half the women could not calculate their relative risk reduction with treatment
- there was no agreement on what was meant by 'good' chances of survival
- 43% of women wanted positively framed messages, 33% negatively framed messages and 25% had no preference
- 89% of women wanted emotional support and 80% wanted to know where to get additional emotional support for themselves and their families
- 95% of women wanted an opportunity to ask questions and have medical terms explained.

6.2 Evaluation studies

Randomised trials or a systematic review of randomised trials, provide the highest quality of evidence about what is effective, in this instance what are effective ways of presenting information for consumers of health services. Controlled studies (that is studies with a control group but which have not allocated the intervention being tested at random), and before-after evaluation studies can also provide evidence of what works, although they are more likely to suffer from bias. In this review we have preferred studies which have a randomised design and which measure outcomes which are important to patients. These outcomes include the actual decision taken, consumers' satisfaction with the decision and consumers' levels of conflict or anxiety about the decision.

6.2.1 Systematic reviews

We identified a protocol for a systematic review of trials in the Cochrane database of systematic reviews. The protocol is called 'Influencing people's experiences of screening' and it aims to identify and assess informational, educational, behavioural or organisational interventions which may minimise anxiety and improve people's understanding and experience of screening. The review is being coordinated by Hilda Bastian on behalf of the Cochrane Consumers and Communication Group. A number of other reviews on closely related topics are being undertaken by this group.

Recommendation

This review should be updated by reference to the systematic reviews undertaken by the Cochrane Collaboration as these are produced.

We identified no other systematic reviews. One annotated bibliography was found which provides summaries of studies of the effectiveness of decision support strategies.⁴³ This bibliography includes some of the studies in the table below (Table 5). Others (published more recently) were identified by our computerised searching.

6.2.2 Randomised trials with outcomes that matter to patients

This section reviews randomised trials of different methods of presenting information to assist consumers with decision making. We identified ten trials published since 1990 and these are summarised in Table 5.^{44 45 46 47 48 49 50 51 52 53} Studies in italics are most useful because they include outcomes which matter to patients such as satisfaction with the

decision or data on the proportion of people who were assisted in decision making, or who made different decisions as a result of the intervention. None of these trials has long term data on whether patients' health outcomes were improved by better decision making. A critical appraisal of the trials which have at least some outcome data and which have been published in full (not just abstracts) is provided in Table 5A. (*See end of document for Tables 5 and 5A*)

The best studies have been conducted by O'Connor et al and have included outcome measures such as knowledge, expectations, the final decision and satisfaction with decision making (measured by the amount of decisional conflict or uncertainty associated with the decision making process). Defining a good quality decision is complex because the decision itself cannot be judged as right or wrong; rather there needs to be an assessment of the experience of decision making which might include the level of uncertainty, the degree of clarity about values, the amount of time taken to decide, adherence to the decision and satisfaction later with the decision. O'Connor et al have developed a scale to measure these aspects of decision making; the scale has been validated and has good reliability.⁵⁴

As can be seen from Table 5 and Table 5A the trials by O'Connor et al on the HRT decision aid and by Wolf et al on a scripted informational intervention on PSA screening are high quality studies. These studies have shown that both the level of satisfaction with decision making and the decision itself (for example interest in screening) is influenced by the presentation of usable, accurate information about risks and benefits of intervention.

Recommendation

Good examples for developing information for consumers are:

- The Ottawa HRT decision aid (O'Connor et al)
- Scripted informational intervention on prostate screening with PSA (Wolf et al).

6.2.3 Longitudinal, uncontrolled studies

These studies are summarised in Table 6. The studies consist of a variety of study designs; one (Moyer et al⁵⁵) is a true cohort study; it examines the relationship between participation in decision making (which is measured at baseline and is present to a greater or lesser extent for each participant) and subsequent outcomes (satisfaction with care, psychological function and fear of recurrence). It is a strong design and also has the advantage of evaluating whether participation in decision making affects health outcomes. The study by Whelan et al has a control group (comprising the first 52 patients) and an intervention group (the last 30 patients) with later measurement of outcomes and so technically is a cohort study, although the groups are non-concurrent.⁵⁶ The remainder are before-after studies with no control group.^{57 58 59 60 61} (*See end of document for Table 6*).

Summary of controlled and uncontrolled studies

Most of the better quality evaluation studies have evaluated decision aids or decision support programs (irrespective of whether they are presented in written or multimedia format). These programs probably result in improved understanding of treatment options, benefits and risks and seem to produce greater satisfaction with decision making.

Recommendation

For those consumers who want to have an active or collaborative role in decision making, decision support programs/aids are likely to improve satisfaction with decision making and ultimately may improve health outcomes.

6.2.4 Descriptive studies

These are studies which simply evaluate information presentations at one point in time with one group of participants. They provide useful, but much weaker evidence about what works in terms of how to present information.

Framing of health information materials

Slaytor and Ward assessed the contents of 58 Australian pamphlets giving information to women about screening mammography.⁶² They found that 60% of pamphlets gave information on the risk of developing breast cancer and only one pamphlet provided information on the baseline risk of dying of breast cancer. Thirteen pamphlets (22%) gave numeric information about the risk reduction associated with mammographic screening; all of these presented the risk reduction as a relative reduction rather than as an absolute risk reduction. Fifteen pamphlets (26%) presented information on false negative rates, but none provided data on false positive rates.

Accuracy and relevance

Smith et al reviewed 168 pamphlets on asthma.⁶³ Of these British Thoracic Society guidelines were applicable to 90; of these 58 were compliant, 21 were >90% accurate and 11 were inaccurate.

Meredith et al compared leaflets and fact sheets on prostatectomy with patients' needs.⁶⁴ Twenty-five fact sheets were examined and 2000 patients completed questionnaires about their treatment. The fact sheets were found to lack uniformity in content, topics of relevance to patients were often omitted and terminology was complex. Patients' experience was at variance with the fact sheets. For example, only one fact sheet discussed the potential consequences of malignancy (29% of patients wanted more information on prostate cancer). Only six fact sheets discussed possible changes in sexual function after surgery, stating that patients would feel no change, but 35% of patients reported a change and 12% admitted to being worried about it.

Readability

Smith et al also assessed readability of the pamphlets using the Simple Measure of Gobbledygook (SMOG) formula which estimates the level of education required to understand the text (see Table 7).ⁱⁱⁱ The reading grade ranged from 5 to 12 (mode 8, mean 9). Given current literacy levels in Britain, they estimated that 97% of these pamphlets would not be comprehensible to the majority of the population.

ⁱⁱⁱ SMOG index is based on the number of words that contain three syllables or more in 30 sentences of the document being assessed. A reading grade is obtained which corresponds to the US educational grading system. By adding 5 to the USA grade, a corresponding UK reading age can be obtained. For example the USA grade 10 corresponds to a UK reading age of 15, that is the expected reading ability of an individual aged 15 years. For further detail see Ley P, Florio T. The use of readability formulas in health care. *Psychology, Health and Medicine* 1996;1:7–28.

Similar work in the United States by Cooley et al analysed the reading level of 63 cancer patients and 30 pamphlets developed by the American Cancer Society and the National Cancer Institute. They found that the reading level of 27% of the patients was less than all 30 of the pamphlets. Meade et al assessed 51 cancer booklets using the SMOG index and found the range of reading grade required for the booklets ranged from 5.8–15.6 with a mean of 11.9.⁶⁵ Booklets written prior to 1985 were more difficult to read, being on average at grade 12.7 compared to a mean of 10.9 for booklets written after 1985. Beaver et al assessed 50 information booklets available to women with breast cancer using the SMOG index and found the mean reading grade of the booklets was grade 10.⁶⁶

Table 7 Reading grades of various documents assessed by SMOG index

	Grade
<i>The Guardian</i> (leader)	13
<i>BMJ</i> paper	14
Stephen King (Insomnia)	8
Insurance policy	14
The Sun (leader)	8
<i>Radio Times</i> (guide)	10

Adapted from Beaver K et al, *Patient Education and Counselling* 199;31:95–102.

Albert and Chadwick⁶⁷ assessed 85 general practice leaflets and found a reading score using the FOG index of 8–17 with a mean of 11.6.^{iv} Of these leaflets, 13% had a reading score of over 14 and 7.6% a score of over 15, which puts these leaflets on a par with papers published in the *BMJ* (See Table 8).

Table 8 Reading scores (as measured by the FOG index) of various pieces of writing

	Score
Arthur Hailey (Strong Medicine)	7
<i>Sunday People</i> (news story)	10
KingsleyAmis (The Old Devils)	11
<i>Daily Mail</i> (news story)	12
<i>BMJ</i> paper	16
<i>Times</i> (leader)	17
Insurance Policy	20

Adapted from Albert T, Chadwick S, *British Medical Journal* 1992;305:1266–8

In Australia Butow et al reviewed five commonly used cancer booklets and found the reading grades (as assessed by SMOG) were 8 (one booklet, 11 (two booklets) and 12 (two booklets).⁶⁸ As was noted earlier, there are no comparable data available about the

^{iv} The FOG index is based on sentence length and number of words of three or more syllables. It calculates a reading age score which corresponds to the expected reading ability of someone of that age.

reading levels of the Australian population. However, if the reading skills of Australians are similar to those of the UK and USA population, then the majority of the population would not be able to read four of these five commonly used booklets.

In summary, these studies and other studies^{69 70 71} consistently show that health information is written at around reading grade 10–12 and that such information is therefore inaccessible to large segments, if not the majority of the population. The findings of these studies are consistent with other reviews on written patient information.^{72 73}

Evidence — is it good for consumers?

Oliver et al studied the introduction of leaflets which summarised the best available evidence about the effectiveness of routine ultrasonography in early pregnancy.⁷⁴ The leaflets were developed by Midwives' Information and Resource Service and the NHS Centre for Reviews and Dissemination as part of the 'Informed Choice' initiative. They summarise the best evidence from systematic reviews, particularly those in the Cochrane Pregnancy and Childhealth database. The leaflets were to be pilot tested at two hospitals but one withdrew from the study because of objections by ultrasonographers which focused on the credibility of the evidence, the likely effect on women's anxiety, the likely disruption to hospital services and reduced uptake of scans. All 14 midwives participating in the study thought the leaflet would be helpful. Twenty-six women participated; first reactions were shock (at the information that 1 in 200 normal fetuses are aborted in error on the basis of ultrasonographic abnormalities), but most women said that it was appropriate to include advantages and disadvantages of routine scanning in the leaflet.

Evaluations and costs of printed health materials

Paul et al reviewed studies of the effectiveness of print material in changing health related knowledge, attitudes and behaviour.⁷⁵ They found that of 17 studies which examined knowledge as an outcome, 14 found that pamphlets were effective in improving knowledge. Six of eight studies found a change in attitudes, but only 16 of 32 studies evaluating effects on behaviour found that behaviour was changed. Other work by Paul and colleagues reviewed 183 Australian pamphlets and found the mean cost of development was \$3797. Seventy per cent of the pamphlets had not been evaluated in any way at all. Less than two per cent had been evaluated by randomised controlled trials.

Recommendation

Currently available information for consumers needs improving. Improvements need to include:

- Information which is important to consumers, eg information about cure rates, spread of disease, treatment options and side effects
- Information which is appropriate to the consumer's choice of decisional role (active, collaborative, passive) — traditional information does not facilitate collaborative or active decision making roles for consumers
- Information which includes baseline risks and absolute risk reductions associated with intervention
- Information which takes account of the variability in the consumer's literacy and numeracy skills

- Accurate information with a strong evidence base
- Presentation formats other than written materials

6.3 The process of developing materials for consumers

Currently there is very little empirical evidence about the impact of information packages designed to assist consumers with decision making on long term health and well being. For example, we do not know whether increased participation in decision making by consumers reduces recovery times or improves survival. Available evidence suggests consumers who want to participate in decision making and are able to do so experience greater satisfaction with care and less uncertainty and conflict about clinical decisions.

Given the current uncertainty, it is not possible to derive from empirical evidence a gold standard against which all consumer information packages should be assessed. Some criteria for developing consumer information have been developed, but it should be stressed that evidence to support the use of these criteria is still largely lacking.

Sets of criteria have been developed by the United Kingdom National Health Service and the Kings Fund.⁷⁶ These sets of criteria are reproduced below (Tables 9 and 10).

Table 9 King's Fund principles for development of information for consumers of health services

- Patients should be given information about their clinical condition and available treatment or management options including non-intervention
- The information package should provide comprehensive and unbiased information about outcomes (risks and benefits) based on a systematic review of the research evidence
- It should outline controversies, uncertainties and gaps in scientific knowledge
- The language and design should be simple, attractive and easily understood
- It should cater for a variety of users, including black people, non-English speakers, people with disabilities etc.
- It should be regularly reviewed and updated
- It should be integrated into a planned program for shared clinical decision making
- Users and professionals should be involved in the development and evaluation of materials

Table 10 **NHS Executive principles for development of information for consumers of health services**

- Information should be up to date, timely, accurate and consistent, and if possible, based on evaluated research with professionals and users involved in its development and evaluation.
- Information should be accessible to all patients in accordance with their information needs and ability to comprehend (ie it must be free, attractively presented and in appropriate language format).
- Information should be integrated into a planned program for shared decision making with feedback from patients and professionals used to refine the information and materials.
- Patients should be able to control how much information they are given at any one time and be enabled by the health care team to understand the information they are given.
- Information must be presented in a way that ensures confidentiality (with the exception of special circumstances) — a patient's explicit consent should be given before disclosure of information to relatives and carers.
- Information should include all available treatments or management options, including non-intervention, with comprehensive and unbiased information about outcomes (risk and benefit) based on a systematic review of research evidence, noting uncertainties and gaps in scientific knowledge.

As a result of their recent review of information materials for consumers (including printed materials, audiotapes and videos) Coulter, Entwistle and Gilbert (for the Kings Fund) have expanded and refined the checklist for patient information materials. It is reproduced in Table 11 below:

Table 11 Checklist for patient information materials⁷⁷

<p>The process:</p> <ol style="list-style-type: none">1. Involve patients throughout the process2. Involve a wide range of clinical experts3. Be specific about the purpose of the information and target audience4. Consider the information needs of minority groups5. Review the clinical research evidence and use systematic reviews where possible6. Plan how the materials can be used within a wider program promoting shared decision making7. Consider cost and feasibility of distribution and updating when choosing media8. Develop a strategy for distribution9. Evaluate the materials and their use10. Make arrangements for periodic review and updating11. Publicise the availability of the information materials <p>The content:</p> <ol style="list-style-type: none">1. Use patients' questions as the starting point2. Ensure that common concerns and misconceptions are addressed3. Refer to all relevant treatment or management options4. Include honest information about benefits and risks5. Include quantitative information where possible6. Include checklists and questions to ask the doctor7. Include sources of further information8. Use non-alarmist, non-patronising language in active rather than passive voice9. Design should be structured and concise with good illustrations10. Be explicit about authorship and sponsorship11. Include reference to sources and strength of evidence12. Include the publication date.
--

While it is plausible that consumers may benefit from involvement in decision making (for example, people may choose a treatment which is better suited to their individual needs and situation), it is also possible that greater consumer involvement in decision making could have adverse effects. Adverse effects might include high levels of anxiety, conflict within the health professional-patient relationship, a sense of guilt or personal failure if a chosen treatment failed to work. Therefore it is essential that information packages for consumers are rigorously evaluated, for both short and long term outcomes and are only used for those consumers who indicate they want an active or collaborative role in clinical decision making.

In the meantime, it seems reasonable to apply the criteria presented in Tables 9, 10 and 11. The criteria are consistent with the information summarised earlier about consumers

needs and preferences and the limited information about effectiveness of information packages and decision support packages for consumers.

In considering the criteria presented above, Entwistle et al argue for some dimensions of quality in addition to the criteria.⁷⁸ These are relevance (including comprehensiveness), accuracy (including appropriateness to the individual), accessibility, comprehensibility, usability and equity. Their discussion raises a number of important issues which are summarised below.

Relevance

The information presented must be relevant to the decision and should include information about all options, all health outcomes resulting from those options and the probabilities with which these outcomes will occur. However, the availability of outcomes might in reality be limited to some consumers, because it has been decided that some interventions will not be provided through health services. Such decisions may be based on evidence of ineffectiveness, lack of cost-effectiveness, or because the health service and staff do not have the skills or equipment to deliver them. This raises the question of whether people should be told of ALL options. In health care systems where price rationing operates there could be serious consequences for both individuals and society if people are advised of treatments which are beyond their financial means.

One treatment option which is not mentioned by the criteria but which may be relevant, is that of entering a clinical trial, especially if the consumer is ambivalent about which treatment to undergo.

Accuracy

Information should include a summary of up to date research evidence. Often this will be problematic because of uncertainties in the evidence and lack of consensus. Dealing with uncertainty can be achieved in a number of ways, for example by providing evidence with a grading about the amount of confidence which can be placed on it (eg good, reasonable, weak), or by excluding research which falls below a threshold of quality, or by providing details of methods and results and encouraging people to critically appraise it.

These approaches will not overcome the difficulties inherent in contentious issues when even information produced according to the highest possible standards remains contestable (as for example with decisions about screening mammography for women aged 40–49 years). In such instances it seems there is little alternative but to provide the relevant research evidence and reassure consumers that the decision ultimately comes down to how each individual values the potential benefits and risks of intervention.

Accessibility, comprehensibility, usability and equity

Accurate and relevant information is of no use if people cannot access, understand and use it. No single information package is going to be suitable for everyone and information will need to be available in several forms if there is to be equity of access and understanding.

To use information packages, people need to be able to:

- understand the information;
- recognise personal values and preferences;

- combine information and preferences in a decision making approach (with or without the assistance of a decision aid);
- communicate effectively with health care professionals.

It is likely that many people will lack these skills and will need assistance. This may be in the form of counselling facilities. Without this, information for consumers may increase inequity in health care: those are most disadvantaged tend to have the poorest health and are also least likely to be able to access, understand and use information packages.

Finally, it cannot be over-emphasised that consumers must be involved throughout the process. Bastian⁷⁹ argues that it is not sufficient merely to involve a consumer representative in the process of developing a guideline. She presents the need for active consumer representatives to be involved from the outset so that high quality consumer input into the objective, target audience and scope of the project is achieved.

Table 5 Randomised trials of information presentations and decision-support interventions for consumers of health services

Author, year of publication	Participants	Interventions tested	Outcome factors	Results	Comments
Boberg 1995	116 men and women with HIV	Computer with CHES (including access to information, support and decision aid)/ No intervention	Use of CHES	Subjects rated CHES positively in terms of ease of use and frequency of use	Despite apparent randomised design there appears to be no comparison of control and experimental groups
Flood* 1996	369 men considering prostate cancer screening	Educational videotape about PSA screening with information on the uncertainty of test results and treatment options/ No video	Knowledge Screening preference Treatment preference Participation in screening	Men viewing the video were better informed, preferred not to be screened, preferred no treatment if cancer was found and were less likely to be tested	
Kroll 1994	252 midlife women	Decision aids presented as: Brochure/ Lecture + discussion/ Active decision support	Knowledge Self-efficacy in relation to health care Decision about taking HRT	All groups improved in knowledge and self-efficacy and the proportion who were undecided about HRT dropped in all groups. No statistically significant differences between groups.	All interventions applied decision analytic principles. There appears to be no gain from more labour intensive decision and approaches.
Llewellyn-Thomas 1995	100 male and female cancer patients	Tape-recorded standard information about chemotherapy trial / Identical information presented via interactive computer program	Patient satisfaction with information presentation. Understanding of information. Willingness to enter trial	No differences in satisfaction or understanding but computer group were more willing to enter the trial	Willingness to enter a trial is not a relevant outcome for this review. However, interesting that the computerised approach did not improve satisfaction or understanding.
O'Connor 1995	100 postmenopausal women	Educational pamphlet / Decision aid both giving information on benefits and risks of HRT	Decisional conflict Decision to take HRT	Decisional conflict lower in decision aid group. Actual decision no different between group.	O'Connor et al have pioneered work on measuring decisional conflict. See text

Author, year of publication	Participants	Interventions tested	Outcome factors	Results	Comments
O'Connor 1996	292 cardiac and respiratory patients	Information about influenza vaccination in Positive frame / Negative frame	Side effects of immunisation Decisional conflict Immunisation decision	Group with positively framed information had lower self reported rate of side effects. Other outcomes no different between groups	
O'Connor 1998	165 postmenopausal women considering HRT	Tailored decision aid (Ottawa HRT decision aid) /	Decisional conflict Expectations of risks and benefits Knowledge Acceptability of intervention Decision to take HRT	Decision aid group had less decisional conflict and more realistic expectations. Knowledge was no different between groups. Decision aid was rated as more acceptable. 58% of each group declined HRT	
Street 1995	60 women with early breast cancer	Interactive multimedia program / Brochure	Knowledge about breast cancer treatment Involvement in decision making	Multimedia group had better knowledge but not more involvement in decisions.	
Van Ruiswyk 1995	136 men considering prostate cancer screening	Pamphlet with prevalence, risk factors and benefits of screening/ Pamphlet with same + information on false positive and false negative rates	Awareness of false positive and false negative results Participation in screening	Knowledge was the same in both groups but more patients in the intervention group reported that screening resulted in more false positive results than they had realised. 87% of controls and 78% of intervention group subjects underwent screening (0.05<p<0.1).	
Wolf 1996	205 men considered prostate screening	Single sentence about PSA screening / Scripted informational intervention included benefits, risks and uncertainties	Interest in screening	Intervention group less interested in screening (OR 0.34, 95% CI 0.19-0.60).	

* Controlled trial but allocation was systematic not random

Table 5A Critical appraisal of randomised trials of decision-support packages

Study	Random allocation	Follow-up (% complete)	Analysis by intention to treat	Comparability of groups at baseline	Comparability of treatment (apart from intervention)	Outcome measured blind	Effect size	Confidence intervals given	Relevance of outcomes (see also Table 5)
Boberg 1995	Yes (method not stated)	8% of intervention group dropped out during early intervention phase. No date on % of control or intervention group completing follow-up measures at 5 months	No control vs intervention group comparisons made	Not demonstrated	No data given	Not relevant as paper only reports usage rates and acceptability of CHES system	No control vs intervention differences reported	No	Acceptance of CHES system. Outcomes on health status, health related behaviours and health services utilisation to follow
Flood 1996	Systematic allocation based on date of clinic attendance	85-93% (depending on clinic) of men returned questionnaire within one week. No data on completeness of follow-up for PSA testing within 2 weeks (data obtained from labs)	Yes	Yes, demonstrated. No differences except small differences in % who had college education. Analysis with adjustment for education did not alter results	No data given	No (self-reported outcomes only)	Large % differences found eg 26% of control and 63% of intervention group reported they would prefer watchful waiting if they developed prostate cancer	Not given	Preferences for prostate cancer treatment, PSA screening and actual screening behaviour

Study	Random allocation	Follow-up (% complete)	Analysis by intention to treat	Comparability of groups at baseline	Comparability of treatment (apart from intervention)	Outcome measured blind	Effect size	Confidence intervals given	Relevance of outcomes (see also Table 5)
Llewellyn-Thomas 1995	Yes (sealed envelopes)	Complete	Yes	Yes, demonstrated	Not demonstrated	No (self-reported outcomes)	No significant differences in satisfaction or information understanding. Probably excludes a very large effect only as power limited	Not given	Main outcome was decision re trial outcome (study is not really about improving shared clinical decision making)
O'Connor 1996	Yes (method not stated)	Complete	Yes	Yes, Demonstrated	Yes	Yes	Small effects – no differences in decision, or decisional conflict but small difference in rates of reported side effects	Not given	Expectations of vaccine risks, side effects and benefits, decisional conflict, immunisation decision and reported side effects
O'Connor 1998	Yes (centrally allocated with allocation concealment)	Complete	Yes	Yes, Demonstrated	Yes	Outcomes self-reported but analysis done blind to intervention group	Quite large effects demonstrated eg up to 17% difference between groups on items in decisional conflict scale	Yes around mean differences but not around differences in proportions	Realistic expectations, decisional conflict, and knowledge
Street 1995	Yes (method not given)	Complete	Yes	Yes, Demonstrated	Yes	Self-reported outcomes + no information on whether the consultation was assessed blind	Large but non-significant eg 76% of intervention group chose breast conservation compared to 58% of control group but difference was not significant (lack of power?)	Not given	Knowledge, optimism, behavioural measures of active participation in the consultation with physician based on analysis of audiotapes. Choice of breast conservation or mastectomy.

Study	Random allocation	Follow-up (% complete)	Analysis by intention to treat	Comparability of groups at baseline	Comparability of treatment (apart from intervention)	Outcome measured blind	Effect size	Confidence intervals given	Relevance of outcomes (see also Table 5)
Wolf 1996	Yes (method not given)	Complete	Yes	Yes, Demonstrated	Yes	Assume not measured blind as outcome recorded by same person who delivered intervention	OR 2.11 and 0.34 for intervention group compared to control on "no interest in screening" and "high interest in screening"	95% CI around OR given	Interest in PSA screening on 5 point scale.

Table 6 Longitudinal, uncontrolled studies

Author, year of publication	Participants	Study factor	Outcomes	Results	Comments
Barry 1995	373 men with benign prostatic hyperplasia	Interactive shared decision making program	Patient rating of program. Consistency between preferences during program and decision about prostatectomy	93% rate the program positively or very positively. Preferences (especially in relation to current symptoms and attitude to post-operative sexual dysfunction) predicted decision making.	Authors conclude that for men with moderate to severe symptoms, attitudes towards current symptoms and prospect of post-operative sexual dysfunction should drive decision making.
Gramlich 1998	103 women with breast cancer	Interactive shared decision making program on treatment options	Patient ratings	Patients found the program clear, balanced, very good or excellent.	
Moyer 1998	Women with early stage breast cancer	Degree of participation in decision making	Satisfaction with care. Psychological function. Fear of recurrence	No associations after 3 months. After 13 months women with more input to treatment decisions were more satisfied with care, but no different in terms of psychological function or fear of recurrence.	
O'Connor 1998	94 women considering HRT	Self-Administered HRT decision aid	Knowledge Expectations HRT benefits and risks Decisional conflict or uncertainty Predisposition towards taking HRT	Mean knowledge scores improved. Proportion of group with realistic expectations increased. Decline in decisional conflict scores. Those who were unsure before using the decision aid were roughly equally likely to move towards or away from taking HRT. Those who had strong views prior to the decision aid were unlikely to change.	
Onel 1998	111 men with localised prostate cancer	Video tape presentation of risks and benefits of treatment options	Understanding of treatment options	Improved understanding of treatment options after video	

Author, year of publication	Participants	Study factor	Outcomes	Results	Comments
Wagner 1995	406 men with benign prostatic hyperplasia	Shared Decision Making program	Preference for surgery or watchful waiting	Before the program about 66% preferred to wait, after program 79% preferred to wait	
Whelan 1995	82 women considering breast irradiation following lumpectomy	Decision board of written material and visual aids (30)/ Standard consultation with no decision board (52).	Understanding of treatment benefits and risks. Sense of being offered a choice. Acceptance of breast irradiation.	Understanding was better in the decision board group. 70% of those in no-decision board group felt they were offered a choice, compared to 97% of those who used the decision board. 95% of both groups had irradiation.	

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