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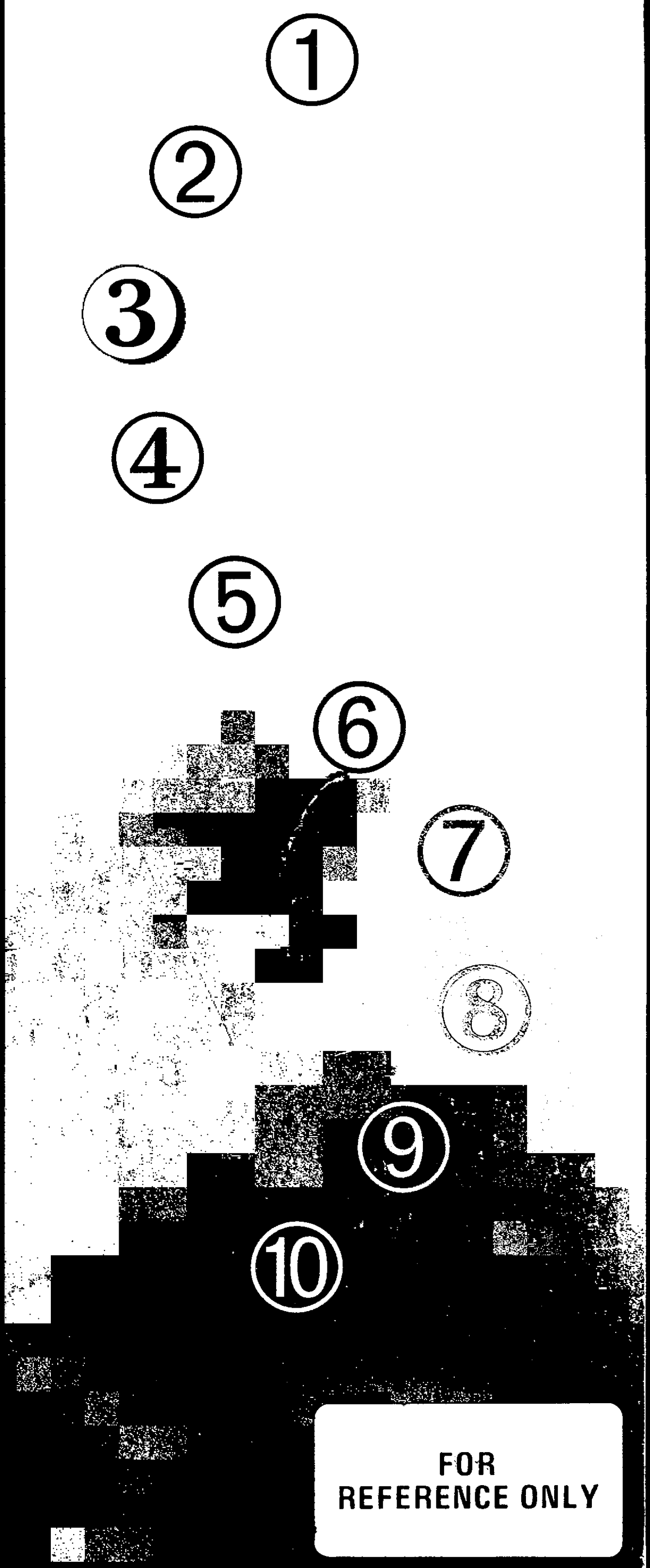
Information about Health Care Effectiveness



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Information about Health Care Effectiveness

An introduction for consumer health information providers

Vikki A Entwistle, Ian S Watt and James E Herring

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About this book

This book is primarily intended for people working in consumer health information services (e.g. telephone helplines, health information shops and community/local health councils) and for students following courses in librarianship or information management. However, the issues it covers will be of interest to a wider audience, particularly health care professionals with a responsibility for sharing information with patients or carers. It aims to enhance the professional's ability to provide good quality information about the effectiveness (risks and benefits) of health care interventions to patients, carers and members of the public. The book provides a sound introduction to the concept of evidence-based health care and considers how consumer health information providers might identify and obtain good quality research-based information about health care effectiveness. It explains why there is currently so much interest in providing people with information about health care effectiveness and involving them in decisions about their care, and highlights some of the practical and ethical issues which this raises for consumer health information providers.

The book has six chapters. At the beginning of each chapter a box lists the main learning objectives for that chapter. A summary of key points is provided at the end of each chapter. Technical terms are explained when they first occur either in the text or in footnotes. A glossary of these terms is provided at the end of the book for quick reference.

References which support statements in the text are listed at the end of each chapter. Those who wish to read about the subject matter of the chapter in more detail are referred in the first instance to the suggestions for further reading, which have been selected for their accessibility and appropriateness to relative newcomers to the subjects.

Chapter 1 relates a story about the treatment of a particular health problem, benign prostatic hyperplasia. It illustrates the importance of good research evidence about the effectiveness of health care interventions and identifies reasons for sharing this information with patients. It also highlights the inadequacy of much of the information which is currently given to patients. This first chapter serves to introduce some of the main concepts which are discussed in more detail later in the book.

Chapter 2 explains the concept of evidence-based health care and considers the reasons underlying the current movement to promote it. It describes the basic features of two methods of evaluating health care effectiveness, randomised controlled trials and systematic reviews, and discusses the use of different health care outcome measures. The chapter concludes by considering the limited extent to which research evidence has been adopted in health care practice and points out some of the ways in which this might be improved.

Chapter 3 outlines the practical steps involved in an evidence-based approach to health care and considers what consumer health information providers might do to ensure they can identify and obtain information about health care effectiveness which reflects the best available research evidence.

Chapter 4 considers reasons for the current interest in providing people with research-based information about health care effectiveness and briefly explores the concept of shared decision making. It considers the roles of clinical health professionals and consumer health information providers, and briefly discusses some of the possible effects of sharing information about health care effectiveness with consumers.

Chapter 5 focuses on the practical issues of how consumer health information providers can best share research-based information about health care effectiveness with consumers. It also highlights some of the ethical and legal issues raised by the provision of information about treatment effectiveness by consumer health information services.

Chapter 6 provides a reference guide to useful sources of information about health care effectiveness. It includes summary information sheets about sources which are known to be based on good quality research evidence.

Chapter 1

Evidence-based health care and the patient's perspective: a case study

This chapter presents a story about the treatment of a health problem: benign prostatic hyperplasia. The story is intended to make you aware of the importance of good research evidence about the effectiveness of health care interventions, and of reasons for sharing this information with patients. It introduces some of the concepts which will be discussed in more detail in later chapters.

OBJECTIVES FOR THIS CHAPTER

When you have read this chapter, we hope that you will be aware that:

- health professionals do not always treat the same health problem in the same way;
- it is not always clear what is the best treatment for a particular health problem;
- there are often good reasons for giving patients information about treatment options and their likely outcomes, and for providing opportunities for patients to be involved in decisions about what treatment they will have;
- many patients in the UK still do not receive good information about treatment options and their likely outcomes.

1.1 Benign prostatic hyperplasia

The prostate gland is an organ found only in men. It lies just below the bladder and discharges fluid which is believed to nourish sperm. Benign prostatic hyperplasia (BPH) is the medical term for enlargement of the prostate gland. The condition is most common in men over 50 years old, and the symptoms may include: difficulty in passing urine (because the swollen prostate gland presses on the urethra); sudden and/or more frequent urges to urinate; leakage of urine; and traces of blood in the urine.

The main treatment options for BPH are surgical removal of part of the prostate gland, or watchful waiting (doing nothing, but keeping a careful watch on symptoms and being alert to any changes). There are also some drugs which can improve symptoms slightly in otherwise healthy men. (Royal College of Surgeons of England, 1995).

1.2 Variations in health care practice

In the mid-1980s, a group of researchers and urologists (doctors specialising in problems of the urinary tract) met in Massachusetts, USA, to discuss the wide variations seen between local hospital districts in rates of surgery for benign prostate problems. In some communities, about 50 per cent of all men had had surgery for BPH by the time they were 85, while in other communities the rate of surgery was only 15 per cent.

The variations appeared to be due to differences in doctors' views about why surgery should be performed for BPH. (Wennberg *et al.*, 1993).[1]

1.3 Beliefs underlying surgical treatments for BPH

Some doctors thought that if BPH was left untreated, it could cause serious problems, such as irreversible kidney disease. Some also thought that it was important to operate on enlarged prostate glands to prevent the patient from getting cancer of the prostate. These doctors therefore thought that early surgery on the prostate gland was justified, even when the symptoms of BPH were only mild. They hoped that surgery could reduce the chance of serious disease, prevent the need for major operations later when patients were older and sicker, and increase life expectancy.

Other doctors did not think that BPH would be so harmful if left untreated. They thought that the main purpose of surgery was to alleviate symptoms and to improve men's quality of life. They were therefore less likely to perform early surgery.

1.4 Who was right? Looking for evidence

In view of the lack of consensus, the research group decided to look at the research evidence to see what the benefits of surgery actually were. They searched the medical literature for studies which could help them answer the following questions:

- Does early surgery for BPH reduce the risk of irreversible kidney disease and improve life expectancy?
- Does surgery for BPH reduce the level of symptoms and improve quality of life?

At that time, there had been no randomised controlled trials comparing the effects (outcomes) of surgery with those of watchful waiting. Randomised controlled trials would have provided the best evidence about the effectiveness of the two treatments.[2] The research group therefore examined the available studies, which followed up men who had either had surgery or had opted for watchful waiting to see what had happened to them. They also examined databases held by medical insurance companies which contained records of payments made for particular operations to see how many of the patients who were operated on for BPH had died or had further operations. The available evidence suggested that early surgery for BPH did not significantly reduce the risk of serious kidney disease (which is fairly small anyway) or improve life expectancy.

The research group found the second question, about the effects of surgery on quality of life, impossible to answer with the evidence available at the time. They could not find any studies which adequately reported how patients felt after surgery for BPH. The argument that prostate surgery alleviated symptoms and improved quality of life was based on the beliefs and clinical experience of some doctors.

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[1] This paper was the main source of the rest of the information in this chapter which relates how the work of the research team in Massachussetts developed (sections 1.2–1.6)

[2] Randomised controlled trials are described in Chapter 2.

The research group therefore decided to carry out their own study to assess the effectiveness of surgery for improving the symptoms and quality of life for men with BPH.

1.5 Patient-focused outcomes research

Firstly, and very importantly, the research team asked patients (including men who were considering surgery for BPH, men who had opted for watchful waiting, and men who had had surgery with both good and bad results) what outcomes mattered to them – what they wanted treatment for BPH to achieve. The patients' responses were used to devise a questionnaire which could be given to people after surgery to assess whether their symptoms had improved, whether they experienced any complications and how they rated their quality of life. The questionnaire was then given to about 400 patients just before they had surgery and then three, six and twelve months afterwards. The findings included:

- About 76 per cent of the men who had had severe symptoms before surgery had only mild or virtually no symptoms after surgery.
- About 17 per cent of the men said they still had moderately severe symptoms after surgery, and 7 per cent thought they were no better off.
- Over 50 per cent of the men experienced problems with sexual function after surgery, and 5 per cent of previously potent men could no longer get an erection.
- 4 per cent of the men started to have problems with dribbling of urine after the surgery.

This evidence suggested that while most men with severely symptomatic BPH are likely to experience a reduction in their symptom levels after surgery, a significant minority will not. It also showed that surgery for BPH carries a risk of problems with sexual functioning.

1.6 Involving patients in treatment decisions

The research group became increasingly aware that BPH affected different men differently. The same symptoms might cause a lot of problems for some men, but not really bother others at all. Similarly, men with BPH could have different opinions about what it was important that treatment did or did not achieve. The research group realised that in order to make a good decision about treatment from the point of view of the individual patient, the individual's views about the different possible outcomes of the treatment options had to be taken into account. They decided to ask the patient to join in the decision-making process.

The research group therefore started to think how they could inform patients about the options for treatment of BPH. They developed interactive videodiscs which included film clips of patients (who were in fact qualified doctors, too), some of whom had opted for surgery and others for watchful waiting. Both the positive outcomes and the complications of surgery and watchful waiting were described on film by patients who had experienced them. The 'interactive' component of the technology involved a computer which allowed people to see as little or as much information as they wanted, and meant that information could be tailored to ensure it was as relevant as possible to the individual watching. For example, information about the viewer's age, the severity of his BPH symptoms and his general state of health could be entered into the computer, and this would determine which information about the likelihood of certain outcomes occurring would be provided to him.

Most of the men who saw the interactive video programme appreciated being given the information and felt able to make choices based on their own values and preferences. Some chose watchful waiting, either because they were not particularly bothered by their symptoms or because they did not want to risk adverse effects such as impotence or other problems with sexual functioning. Others chose surgery because it was more important to them to have an opportunity to reduce their symptoms.

1.7 What's happening in the UK?

A national audit of surgical removal of the prostate gland in the UK was conducted recently by the Royal College of Surgeons (Emberton *et al.*, 1995). Its findings included the following.

- There were unexplained variations in the way in which signs and symptoms were investigated before surgery. For example, some men had their urine flow tested but others did not. Also, different surgical units seemed to decide to surgically treat people with different levels of symptoms.
- Older men and men from higher socio-economic groups were more likely to undergo surgery with fewer or milder symptoms.
- 12 per cent of men being operated on were having a second or subsequent prostate operation.
- 61 per cent of surgeons gave printed information to patients before they underwent surgery.

The audit team thus identified several variations in practice which warranted further investigation. It was not clear whether these variations in practice were associated with variations in patient outcomes.

1.8 Patient information in the UK

The interactive video developed by the US team described above has been tested among a small sample of patients in the UK. Most of the men who were offered the chance to view the video chose to do so, and most said they found the interactive video an acceptable method of receiving information. Just over 70 per cent of the men who saw the interactive video programme said it definitely helped them with their treatment decision. Most of their general practitioners also found the video helpful because it was easier to discuss relevant issues with patients who had been informed by watching it (Shepperd *et al.*, 1995).

A research team at the Royal College of Surgeons recently gathered information about treatment and recovery experiences from over 4000 men who had undergone prostate surgery (Meredith *et al.*, 1995). Over 800 of these men also commented on the information they thought should be given to patients. The research team asked surgeons who were participating in the national prostatectomy audit to provide them with copies of any printed information which they gave to patients. They studied 25 different factsheets, ranging in style from professionally printed brochures to almost illegibly photocopied A4 sheets.

The following quotations describe some of the findings from the study of factsheets given to patients.

- 'Surgery was discussed in 22 sheets as though it was both inevitable and always effective in resolving symptoms'.
- 'Fourteen factsheets described the likely outcome of the operation as alleviating all symptoms. The 11 others omitted any mention of outcome and gave the impression that symptoms would be totally relieved'.
- 'The possibility of non-resolution of critical symptoms or worsening of symptoms as a result of surgery was addressed by four factsheets. Among the subjects discussed were incontinence and irritable bladder. Only one factsheet mentioned the possibility of death in elderly men'.
- 'Potency was addressed in 17 factsheets, although only six of them mentioned the possibility of the operation causing impotence in some cases. The remaining 11 indicated that no change in potency would occur as a result of this operation'.

Some topics which many patients wanted information about were not addressed at all in some of the factsheets. Some of the information in the factsheets contradicted the experiences reported by the men who were questioned as part of the same study. For example:

- 32 per cent of the men questioned experienced problems getting an erection after their prostate surgery.
- 36 per cent of the men reported either a constant or an occasional change in sexual sensations after the operation.
- 12 per cent of the men were either very worried or quite worried about changes in their sexual function since the operation.

1.9 Shortcomings in patient information provision

The authors of the study of patient information about prostate surgery concluded that there was a mismatch between the information being given to patients by surgeons and the information that patients needed. For many topics, particularly sexual functioning, the information given did not reflect the experiences actually reported by patients.

Similar shortcomings are likely to be found in patient information about treatments for other health problems too. Thus even those patients who receive written information during the course of their care might not receive adequate information. The authors of the study of patient information about prostate surgery suggested that one possible reason for this was that patient information sheets tend to be written by clinical staff, who write them on the basis of their own knowledge and what they think patients should know.

They might thus fail to address issues which are important to patients. In particular, they might tend to omit information about health care outcomes because they think it might alarm them, or because they think people don't need to know about rare complications which are 'unlikely' to affect them. However, it is increasingly recognised that many people want information about the possible outcomes of their treatment. It therefore seems important that mechanisms are developed to ensure these needs are met.

Subsequent chapters will explore the concept of evidence-based health care, research about health care effectiveness, patient needs for information about health care effectiveness, good quality sources of such information and the possible roles of consumer health information providers in helping to meet information needs.

KEY POINTS

- It is not always clear what is the best treatment for a particular health problem.
  - There may not be any/enough good research evidence about the effectiveness of particular treatments.
  - Treatments may affect a variety of aspects of health and well-being. Decisions about which treatment is best may involve trade-offs between different risks and benefits.
  - The best course of action may depend on the viewpoint of the patient.
- There is often a mismatch between the information given to patients by health professionals and the information that patients need.
- Information about the outcomes of health care may often be absent from patient information materials.
- When information about the outcomes of health care is included in patient information materials, it may not always be accurate.

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Further reading

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Chapter 2

Evidence-based health care

This chapter explains what is meant by the phrase 'evidence-based health care' and describes the rationale behind the current movement to promote it. It goes on to consider how the effectiveness of health care interventions is evaluated and describes the basic features of randomised controlled trials and systematic reviews. Some attention is then given to the health care outcomes which have been investigated. The chapter concludes by considering the limited extent to which research into health care effectiveness is reflected in practice, and ways in which this might be improved. The practical steps involved in an evidence-based approach to health care are considered in Chapter 3.

OBJECTIVES FOR THIS CHAPTER

When you have read this chapter, we hope that you will be able to:

- explain what evidence-based health care is and why it is important;
- understand the basic features of randomised controlled trials and systematic reviews;
- recognise that not all health care interventions have been well evaluated;
- recognise some of the limitations of available health care outcomes information;
- realise that it may not be possible to provide reliable answers to all questions about how well health care interventions work with currently available evidence;
- understand some of the reasons why health care practice doesn't always reflect available research evidence, and be aware of ways in which better use of research evidence in health care might be encouraged.

2.1 What is evidence-based health care?

Evidence-based health care can be defined as an approach to health care which involves finding and using up-to-date research into the effectiveness of health care interventions to inform decision making. A recent article by some of the most active proponents of evidence-based medicine defined it thus:

> *Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions abut the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external evidence from systematic research. (Sackett* et al., *1996)*

Evidence-based health care is health care which has been rigorously tested in practice and been shown to be effective.[1]

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[1] By 'effective', we mean likely to do more good than harm.

If we do not have evidence about the effectiveness of different forms of health care:

- decisions about how to treat people will be based primarily on theory and beliefs about how interventions work, rather than on knowledge about what actually works;
- people may be given interventions which are unlikely to benefit them and which may harm them;
- people may not be given interventions which are likely to benefit them;
- resources may be wasted, as the limited amount of money available for health care may be spent on care that produces little or no benefit.

Many people might assume that all health care is evidence-based. After all, modern medicine has a highly scientific aura, and the evidence-based approach to health care seems an obvious one. However, not all health care decisions are based on research evidence about the effectiveness of different health care interventions, either because appropriate research evidence is not available or because it is not used.

We should also note that even the best available research evidence cannot remove the uncertainty attached to many health care decisions. This is considered further in section 3.8.

2.1.1 Devising and evaluating health care interventions

Health care interventions are usually devised on the basis of what is known about the structure and functions of human bodies and the nature of disease. If we have worked out what has gone wrong with the body, we can think about how it might be fixed. This may be an appropriate way to invent treatments, but the human body is very complex, so our predictions, which are inevitably based on a limited understanding of how it works, may not be fulfilled. What we think should happen in theory might not actually work in practice. It is therefore important that health care interventions are tested on (a limited number of) real patients before they are introduced on a large scale. This is why pharmaceutical drugs have to pass certain safety tests and be shown (at least to a limited extent) to do some good in clinical trials before they are licensed for use.

There have been cases of interventions which seemed likely to work being introduced into practice and ultimately doing more harm than good. For example, thalidomide was introduced as a sleeping drug which was believed to be suitable for pregnant women, although it had not been rigorously tested on them. In practice, it caused limb deformities among many babies born to women who took it while pregnant (Mellin & Katzenstein, 1962). In contrast, some interventions which were initially thought to be unpromising have turned out to be very useful. For example, many people were sceptical about and reluctant to use clot busting (thrombolytic) drugs, but these have been shown to be effective in reducing the risk of death from heart attack (Antman *et al.*, 1992).

An evidence-based approach to health care recognises that while an understanding of the basic mechanisms of disease is necessary, it is an insufficient guide to clinical practice because we cannot really know what effect a treatment will have until it has been tested in practice. Evidence-based health care emphasises the observed, rather than just the theoretically predicted effects of treatments. It stresses the importance of rigorous evaluations of what actually happens when particular interventions are given to people with particular conditions.

2.1.2 Some health care interventions have never been evaluated

Some health care interventions have never been evaluated. The US Office of Technology Assessment estimated in 1978 that only 10-20 per cent of currently used interventions had been shown to be effective by controlled trials. This estimate may have been unduly pessimistic because it probably focused on high profile, expensive procedures, and because it included interventions which were rarely used. A study conducted among NHS patients in a medical unit in Oxford found that the primary treatments given to 82 per cent of the patients had either been shown to be effective by randomised controlled trials or were unanimously thought by the medical team to be supported by convincing non-experimental evidence (Ellis *et al.*, 1995). However, the encouraging results of this study may not be generalisable to many 'average' medical wards because the medical team in the study had explicitly adopted an evidence-based approach to health care and made conscious efforts to use research evidence of effectiveness when making treatment decisions.

The point remains that some health care interventions have never been evaluated. Further, the quality of studies of health care interventions varies. Not all research into the effectiveness of health care has been well designed, well executed and well reported, so not all research evidence is as reliable or as useful as it might be, and it may be difficult to draw any firm conclusions from it.

A lack of conclusive scientific evidence about what forms of health care work best for particular conditions is one of the reasons for the many differences in the way health care is practised between and within different countries (Smith, 1992). It has become increasingly apparent that there are large geographical and cultural variations in the practice of health care which do not simply reflect the different health problems experienced in different countries, regions or societies.

For example, more coronary artery bypass grafts and hysterectomies are performed per head of population in the USA than in the UK, and this is not simply explained by differences in the amount of heart disease or gynaecological problems between the two countries or the amount of money available for health care. In France, far more drugs are prescribed in the form of suppositories than they are in the USA or the UK. Fashions in health care also come and go over time. Women giving birth today are unlikely to have their pubic hair shaved, although that would probably have been the norm when they themselves were born. Children today are less likely to have their tonsils removed than their parents were, although they might be more likely to have grommets inserted for glue ear (see Smith, 1992; Payer, 1990). Greater awareness of these variations in practice has raised questions about scientific evidence for the effectiveness of health care interventions, and was one of the triggers for the current emphasis on the importance of evidence-based health care.

2.1.3 What is new about evidence-based health care?

It has long been known that treatments do not always work in practice in the way they might be expected to do in theory. What is new about the current movement to promote evidence-based health care is the growing realisation that the effectiveness of *all* health care interventions (rather than just drugs) and different ways of organising health care should ideally be evaluated by rigorous research, and that decisions about health policy and day to day health care practice should reflect the best available research evidence.

Many doctors are used to making decisions about how to treat people on the basis of information they were given during their first training (which may rapidly be superseded), theoretical predictions, and their clinical experience (a limited number of unsystematic observations). The newly stated principles of evidence-based health care encourage health professionals to develop a systematic approach to identifying and using research-based information for clinical decision making. However, we should stress that they do not deny the importance of clinical experience for interpreting and applying the results of rigorous research to decisions about individual patients.

Two other developments associated with the recent emphasis on evidence-based health care are also worth mentioning. Firstly, there is a growing awareness that some forms of evidence are better than others, and that two types of research in particular, randomised controlled trials and systematic reviews, can provide very good information about the effectiveness of different treatments. A basic introduction to these to types of research is provided in section 2.2. Secondly, it is increasingly acknowledged that health care interventions should be evaluated in terms of outcomes which are important to patients, not just those which are of interest to doctors or are easy for researchers to measure. Patient-focused outcome measures are discussed further in section 2.3.

2.2 How do we establish whether and how well a health care intervention works?

If left untreated, diseases follow a 'natural history' and symptoms might improve or worsen over time. Some diseases are usually self-limiting. For example, if we get a bout of 'flu, we might feel particularly unwell for a few days and take to our bed, but we can usually expect the symptoms to disappear without any medical intervention.

Question: If you took a new 'flu remedy and got better, how would you know whether the remedy had helped or not?
Answer: With only your own experience to judge by, you could probably not tell whether the 'flu remedy helped your recovery, or whether you would have got better just as quickly without it.

Of course, a few health care interventions have such instantly dramatic effects that it is easy to see they have worked. For example, when penicillin is given to people with severe infections, or glucose to a diabetic in a hypoglycaemic coma, a quick and remarkable recovery is often observed. This can be attributed with a fair degree of certainty to the treatment given.

However, most health care interventions have much smaller effects which can only be seen over a period of time. It is therefore usually difficult to know purely by observation whether a treatment actually *causes* an improvement in a person's health, or whether the improvement might have occurred anyway without it. Researchers usually assess how well health care treatments work by *comparing* the changes in health seen among a group of people who *are* given the intervention with those seen in another group who *are not*. It is important that the groups of people they compare are similar: if there is no difference between the groups at the start of the trial, then it is more likely that any differences between them at the end of the trial are due to the different interventions they were given. The best basic study design for assessing the relative effectiveness of two therapeutic interventions is the randomised controlled trial.

2.2.1 Randomised controlled trials

A basic randomised controlled trial (RCT) involves assigning people randomly to two groups: the experimental group and the control (or comparison) group. A process of random allocation is used to ensure that the two groups are as similar as possible at the start of the trial. It may sound a bit odd, but in fact 'chance' is more likely to shuffle a group of people as evenly as possible than researchers, who might tend to introduce all sorts of bias into their sorting procedures. The experimental group are given the (new) intervention which is being tested and the control group are given an alternative, often either a current standard treatment or a placebo[2] treatment. The two groups are followed up to see if there are any differences between them. This allows the effectiveness of the two interventions to be compared.

Some randomised controlled trials give us more reliable information than others, for example because they involve more people, or because they are better designed and carried out. Some of the features of RCTs which are likely to affect the quality or strength of the evidence they provide are discussed in section 3.6.2. For now, we should note that small randomised controlled trials may be limited in scope, and their results might be inconclusive because we cannot rule out the possibility that they occurred by chance. It may help you to understand why small trials are more susceptible to the play of chance than large ones if you consider the following: if you tossed a coin three times and got three heads, you would probably think this was just due to chance. However, if you tossed a coin 300 times and got 300 heads, you might start to wonder whether there was something special about the coin because it landed heads up so consistently.

2.2.2 Systematic reviews

The aim of a systematic review (also called an overview) is to provide as clear and unbiased a summary of the evidence available to answer a specific question. Systematic reviews are useful because the results of individual research studies on a particular topic may be

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[2] A placebo treatment is a pill, potion or procedure which would not be expected to be effective because it has no known active drug ingredients or specific healing properties. It may be unethical to use placebos in control groups if reasonably effective treatments already exist. In these cases, the new treatment of uncertain effectiveness would be compared with existing treatments rather than placebos.

inconclusive and may even appear to contradict each other. Systematic reviews allow the results of relevant individual research studies to be brought together in a scientific way. This may enable more accurate estimates of the effectiveness of a particular intervention to be produced because a larger number of observations can be used. Systematic reviews may also help identify those areas of health care in which current evidence is not conclusive enough to allow us to answer questions about effectiveness, and may clarify in which areas further research is needed.

Systematic reviews are carried out to answer specific questions. They involve a literature search, which should be as comprehensive as possible, to identify all the relevant research, including unpublished research reports, and reports appearing in grey literature as well as those appearing in major journals. The methods of the literature search should be documented so that users of the review can ascertain how likely it was to have identified all the relevant research studies. Good systematic reviews then use explicit criteria to determine which individual studies will be included in the review, what information will be extracted from each study, and how that information will be assessed and combined to provide a valid and reliable summary of available evidence.

A systematic review which involves a quantitative synthesis of the results of individual studies is often called a meta-analysis. Meta-analyses use statistical techniques to combine the numerical results (such as effect sizes) of individual studies to produce one summary numerical estimate.

2.3 Thinking about health care outcomes

Health care treatments have one or more of the following goals: to save or prolong life; to relieve symptoms; or to improve quality of life. Treatments with different goals should be judged according to different criteria because we expect them to have different outcomes. However, the unintended consequences must be assessed as well as the intended ones if we are to have a complete picture of the effectiveness of a treatment. While it is relatively easy to assess whether treatments prolong life (because death is quite a straightforward outcome to record), it is much harder to know how to measure symptom relief or quality of life (Coulter, 1994).

Health care can have a variety of effects, for example on an individual's health, on their satisfaction with health care services, on their productivity, their relationships with others, and on the wider community in which they live and work. In order to judge the effectiveness of a particular intervention, we might want to ask a variety of questions about the impact it has in medical, social, economic or personal quality of life terms. Outcome measures might include the following.

- Mortality rates (how many people who received the intervention died?).
- Physical or biochemical indicators of bodily states (e.g. blood pressure, blood sugar levels).
- Measures of health service use (e.g. length of stay in hospital, number of visits to GP).
- Functional status measures (e.g. ability to walk up stairs, ability to shop and cook).

- Self-reported quality of life measures (e.g. improvements in symptoms, perceptions of well-being).

2.3.1 What kind of outcomes information is available?

Research into the effectiveness of health care interventions involves measuring selected outcomes at specified times after the interventions were given. Some outcomes have been studied more frequently than others. Medical researchers have tended to use death rates, physical and biochemical measurements, and indicators such as length of hospital stay or rates of re-admissions as the main outcome measures because these are relatively easy to observe and record reliably. Studies which use these outcomes also tend to need less patients to achieve a statistically significant result. It is harder to devise reliable measures of people's quality of life, and self-reported measures of how people feel are difficult to standardise, so these outcomes have been less frequently studied.

This means that much of the available outcomes information tends to cover mortality and physical complication rates, and only a limited range of other outcomes. Many of the quality-of-life-related outcomes which patients consider important have not been rigorously studied. For example, in a systematic quality assessment of 38 randomised controlled trials of medical treatments for damage to peripheral nerves caused by diabetes, Cavaliere *et al.* (1994) found that the primary outcome measure in almost all studies was one chosen because it was easy for researchers to measure (for example, nerve conduction velocity) rather than because it was it was a good indicator of how patients' lives were affected. Only two trials recorded the development of skin ulcers.

The call is increasingly heard for the patient perspective to be taken into account when evaluating health care interventions, and also for greater patient involvement in the setting of the research agenda (Neuberger, 1993; Chalmers, 1995). People are beginning to realise the importance of ensuring that future research addresses questions of relevance to patients. Consumer health information providers who are aware of the kinds of questions which people are asking might be able to make an important contribution to the shaping of research agendas.

2.3.2 Long-term outcomes and rare adverse effects

The timescale over which risks and benefits are seen may vary between interventions, and the effectiveness of a particular intervention may vary over time. For example, when comparing surgical and drug treatments for the same condition, the surgical option might have poorer short term outcomes (due to complications of the surgery), but may have better longer-term outcomes. The effects of drug interventions to prevent heart attacks may only start to be seen after several years, while the adverse effects associated with some drugs may not manifest themselves for decades.

Information about the long-term effects of particular interventions, and about relatively rare adverse effects is often difficult to come by as these outcomes are difficult and expensive to study systematically (Shanner, 1995).

2.4 Getting evidence-based health care into practice

We have already seen that research evidence about the outcomes of health care, particularly about long-term outcomes and those outcomes most relevant to people's quality of life, may be lacking. Even when good research evidence exists, it isn't always quickly taken up into routine clinical practice. Antman and colleagues (1992) assessed all the evidence about treatments for myocardial infarction (heart attack) which had been available in particular years and compared this with the recommendations made by clinical experts in textbooks and other key articles published at about the same time. They found some important discrepancies between the experts' recommendations and the best available research evidence. For five out of six treatments which were shown to reduce death rates in hospital, it took several years for experts to recommend the treatments with any consistency. Thirteen years after clot busting drugs had been shown to be effective by randomised controlled trials, they were still only recommended by half the expert sources.

2.4.1 Why doesn't health care practice always reflect the available evidence?

There are several reasons why health care practice doesn't reflect research evidence as much as we might like it to. These include the following.

- Relevant research-based information may not be available or may be inaccessible to health care professionals.
- Health professionals have not traditionally been trained to seek out and use evidence of effectiveness when making clinical decisions.
- Some effective interventions require particular skills or resources which may not be readily available.
- There may be pressures, for example from commercial interests, to practice certain forms of health care rather than others.
- Behaviour change is rarely simple.

We mentioned earlier that some health care interventions have never been evaluated and that reliable information about their effectiveness simply isn't available. Thus, on the one hand, there often simply isn't enough information available to allow an evidence-based decision about how to treat a particular patient. On the other hand, there is so much medical information available – about 4 million articles are published in biomedical journals each year – that it is impossible for health professionals to keep up with it all. The sheer volume of information available can also make it difficult to find the best, most relevant information. This is discussed further in Chapter 3, and Chapter 6 provides practical information to help locate good research evidence of effectiveness.

Some research findings might be difficult to implement because they require special skills, equipment or resources which are not readily available. For example, there is clear evidence that among pregnancies in which the baby remains in a breech presentation (the wrong way round, making delivery difficult) towards the end of pregnancy, the rate of normal deliveries can be increased by a process known as external cephalic version, which involves putting hands on the mother's abdomen and turning the baby from the outside (Hofmeyr, 1994). However, many obstetricians and midwives have not been trained to perform the intervention.

People are often slow to change their behaviour, and there may be a variety of barriers (attitudinal, social, cultural, financial, etc.) to them doing so. Simply giving people information often isn't enough to make them change their behaviour, even if the information convinces them that they probably ought to do so (Lomas & Haynes, 1988). You are probably aware of the amount of research information available about the harmful effects of smoking on health and the numbers of people who continue to smoke.

2.4.2 Encouraging health professionals to practice evidence-based health care

As well as general encouragement for the widespread adoption of an evidence-based approach to health care, there have been various attempts to change specific types of health care practice to bring them more into line with research evidence. Such initiatives are usually either attempts to ensure that as many patients as possible who might benefit from an intervention known to be effective are given that intervention, or to ensure that no one is given an intervention which research has shown to be harmful. For example:

- aspirin reduces the chances of dying by about a fifth for patients who have had a heart attack, and reduces the changes of having another heart attack or a stroke by about a quarter (NHS Centre for Reviews and Dissemination, 1995). It is an easy, cheap treatment to give, and therefore it seems reasonable to promote its use in appropriate cases.
- a certain type of suture material which is often used to repair tears or surgical wounds occurring during childbirth has been shown to be associated with a greatly increased risk of long-term pain, particularly during sexual intercourse (Johanson, 1994). Given that other suture materials are available, it seems reasonable to argue that these should be used in preference.

Initiatives to encourage the adoption of specific health care practices in appropriate situations may involve a variety of activities. These could include: dissemination of information in various formats and via various channels; continuing professional education courses; clinical guidelines; reminder systems; policy statements (issued at national or local levels); restrictions made by health care funding bodies; specification of practice requirements in health care contracts; financial incentives, and so on. An approach of particular interest to readers of this series involves the use of patients (or potential patients) as change agents. It is possible that patients can be taught to expect, or encouraged to demand, those forms of health care which have been shown to be effective.

The effectiveness of different approaches to research implementation are unknown, and there is now a programme of research within the NHS which is devoted to investigating how health professionals can be encouraged to ensure that their practice reflects the best possible research evidence (Department of Health, 1995).

KEY POINTS

- Evidence-based health care involves finding and using up to date research into the effectiveness of health care interventions to inform health care decision making. Evidence-based health care is health care which has been rigorously tested and shown to be effective.
- Randomised controlled trials involve assigning people randomly to experimental and control groups and comparing their outcomes. Randomised controlled trials are usually the best way of assessing the relative effectiveness of the two treatments.
- Systematic reviews aim to provide an unbiased summary of available research evidence. They involve thorough literature searches and systematic methods of extracting and combining information from relevant research reports.
- Researchers have not always studied the outcomes of health care which affect patients' quality of life. Long-term outcomes and rare adverse outcomes are very poorly understood.
- Health care practice does not always reflect available research evidence. This may be because of: the inaccessibility of relevant information; the nature of professional education; lack of skills and resources; individual and social barriers to behaviour change.
- Attempts to encourage the use of specific research evidence in practice include: dissemination of information; practice guidelines; continuing professional education; generation of informed demand from patients for health care which has been shown to be effective.

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Chapter 3

What does an evidence-based approach to health care and consumer health information provision involve in practice?

This chapter outlines the steps involved in an evidence-based approach to health care and considers what consumer health information providers might do to ensure that any information about health care effectiveness which they give reflects the best available research evidence.[1] It concludes by pointing out that even good quality research evidence does not necessarily make decisions about health care simple!

OBJECTIVES FOR THIS CHAPTER

When you have read this chapter, we hope that you will be able to:

- appreciate in broad terms what evidence-based health care involves in practice, and how this differs from more traditional approaches to health care;
- be aware of two basic strategies which consumer health information providers might use to identify relevant and reliable information about health care effectiveness, and appreciate the skills and resources required by these strategies;
- be aware of the key features of randomised controlled trials and systematic reviews which may affect their quality and usefulness;
- understand that research evidence about health care effectiveness may not be easy to apply in practice, and be able to explain some key points which should be taken into account when using it to make decisions about treatments.

3.1 What does evidence-based health care involve in practice? A scenario

A wide variety of questions about diagnosis, risks and benefits of interventions, prognosis[2] and quality of care arise during the practice of health care. Many of these can be addressed using an evidence-based approach. The following description is an edited version of a clinical scenario about prognosis and treatment which was used in an early article about evidence-based medicine. It contrasts the evidence-based 'way of the future' with the more traditional 'way of the past' (Evidence Based Medicine Working Group, 1992).

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[1] Some consumer health information services consider the provision of information about health care effectiveness as beyond their remit, although under *Health Service Guidance* (95) 44, those using the national freephone number are required to provide it. This chapter considers how those services which do provide information about health care effectiveness can ensure it is as reliable as possible.

[2] 'Prognosis' refers to the future course of an illness.

> *A junior doctor admitted a 43-year-old man to hospital. The man had had a grand mal seizure (fit), which was confirmed by witnesses, and was given an anti-convulsant drug. The junior doctor asked relevant questions about the man's health prior to the fit (which was good), and arranged several examinations, including a computerised tomographic head scan, the results of which all appeared normal. The man was very worried that he would have another seizure and wanted to know his prognosis. The junior doctor did not know the prognosis following a first seizure.*

If the junior doctor stuck to the 'way of the past', the scenario might continue thus:

> *The junior doctor asked a senior doctor what the risk of the patient having another seizure was. The senior doctor said the risk was high, although he couldn't put a figure on it. The junior doctor gave this information to the patient, who left with a vague sense of trepidation about his risk of having another seizure.*

In contrast, if the junior doctor adopted the 'way of the future' (the evidence-based approach), the scenario would continue as follows:

> *The junior doctor went to the library and used* Medline *to search for literature about the prognosis and recurrence of epilepsy. She found references to 25 journal articles, one of which was directly relevant to the patient concerned. She checked to make sure that the study reported had used valid methods to investigate prognosis. The results of the study showed that the patient's risk of having another seizure within a year was 43–51 per cent, and of having another seizure within three years was 51–60 per cent. However, if he did not have a seizure within 18 months, there would be a less than 20 per cent chance that he would have another one. The junior doctor gave this information to the patient and suggested that he took an anti-convulsant drug for 18 months to reduce his chances of another seizure, then reviewed whether he needed to keep taking it if he remained seizure-free.*

3.2 What does evidence-based health care involve in practice? Basic steps

An evidence-based approach to decision making when faced with a particular clinical problem is usually described in terms of four steps which we will refer to as strategy A.

Strategy A:

1) Formulate an appropriate question
2) Search the medical literature to locate relevant research evidence
3) Critically appraise the research evidence to assess its relevance and validity
4) Use the best available research evidence to make decisions about health care

However, some information sources which are now being produced to encourage the adoption of evidence-based health care make steps 2 and 3 much simpler for practitioners by partially incorporating them into their production processes. For example, the *Cochrane Database of Systematic Reviews* and the *Effective Health Care Bulletins* contain systematic reviews which have all been conducted to rigorous standards. The reviewers have undertaken thorough literature searches to identify relevant primary studies, have critically appraised these studies and have used appropriate methods to summarise their results. The *NHS CRD Database of Abstracts of Reviews of Effectiveness* contains structured abstracts of good systematic reviews together with critical commentaries which highlight factors to take into account when interpreting and using the evidence presented. The *ACP Journal Club* presents structured abstracts of good quality systematic reviews and randomised controlled trials which are considered important to health care decision makers in the field of internal medicine, and includes commentaries discussing the appropriate application of the findings in clinical settings.[3]

The existence of these sources of information, which are produced by researchers with expert critical appraisal skills and which present either rigorous summaries of the available research or 'sifted' collections containing only good quality research, means that health professionals can adopt what we will call strategy B as part of an evidence-based approach to decision making:

Strategy B:

1) Formulate an appropriate question
2) Search databases, journals or bulletins which include only high quality systematic reviews, randomised controlled trials or the best available research evidence and which have critical appraisal built into their production process, to locate relevant research evidence
3) Use the best available relevant research evidence to make decisions about health care

3.3 An evidence-based approach to consumer health information provision

It is possible that someone might contact a consumer health information service wanting information about how likely it is that a 43-year-old man (perhaps themselves, their husband or their friend) who had just had a first grand mal seizure and had been treated in hospital and discharged with a prescription of anti-convulsant drugs, could have another fit. It is also possible that the person had decided to contact the consumer health information service either because the hospital doctor and their GP had given conflicting information, or because both doctors were either unwilling or unable to tell them anything more than that there was nothing obvious wrong (the computerised tomography scan was normal) and that they should keep taking the anti-convulsant drugs.

The 'way of the past' of the consumer health information provider faced with such an enquiry might have been:

- to see what information they could find in a respected medical textbook;

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[3] These and other information sources which focus on high quality evidence are described in more detail in Chapter 6.

- to see what information they could find in patient leaflets about epilepsy;
- to contact a national or local epilepsy group to ask for information and advice;
- to contact a doctor who served as an advisor to their service and ask what he thought they should tell the enquirer;
- to search the Medline database to find any relevant and readable information.

These approaches might, but quite possibly might not, have provided them with information reflecting the best available research about the recurrence of seizures after a first seizure in otherwise healthy men. It is particularly important to note that relatively few patient information materials provide research-based information about the outcomes of treatment. Consumer health information services might thus need to find this information first in sources which are primarily geared towards health professionals or academics.

The evidence-based 'way of the future' which is being promoted in clinical settings could, at least to some extent, be adopted by consumer health information services to ensure the information they provide is as accurate and reliable as possible. For consumer health information providers, the two strategies might be better written as follows:

Strategy A for consumer health information providers:

1) Formulate an appropriate question
2) Search the medical literature to locate relevant research evidence
3) Critically appraise the research evidence to assess its relevance and validity
4) Provide the best possible information, and guidance about its use[4]

Strategy B for consumer health information providers:

1) Formulate an appropriate question
2) Search databases, journals or bulletins which include only high quality systematic reviews, randomised controlled trials or the best available research evidence and which have critical appraisal built into their production process to locate relevant research evidence
3) Provide best possible information, and guidance about its use[4]

In the next few sections we discuss the steps of strategies A and B in a bit more detail and comment on some of the issues they raise for consumer health information providers.

3.4 Formulating an appropriate question

The first step of an evidence-based approach, whether strategy A or strategy B is adopted, is to formulate a question which makes explicit:

- the characteristics of the patient(s) in question, including their health status;

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[4] People may need help to understand, interpret and use research based information, which often comes in the form of probabilities and risk statistics. Sections 3.9 and 5.8 discuss this further.

- the interventions which might be considered, including all the alternatives and watchful waiting;
- the outcomes of interest (related to the aims of the interventions).

We can then ask specifically: 'What are the likely effects of these interventions on these outcomes in these patients?'

In the case of the enquiry about prognosis after a first grand mal seizure, the known characteristics of the patients are: male, aged 43, who has experienced first grand mal seizure and whose computerisd tomography head scan is normal. The intervention is a particular type of anti-convulsant drug (other interventions of interest might include different anti-convulsant drugs or no medication). The main outcome of interest is seizure recurrence, although other outcomes, particularly unwanted side-effects, may also be important.

When full information about the patient, interventions and outcomes of interest is spontaneously offered by enquirers, it will be relatively easy for consumer health information providers to formulate a specific question. However, it is quite likely that in many cases consumer health information providers will need to seek information from the enquirer to clarify, for example, the patient's diagnosis and other salient characteristics, the treatment options they are already considering (or are particularly interested in), and any outcomes which are of particular importance to them. A structured approach to question formulation using the three dimensions (patient, interventions, outcomes) might make this easier.

However, it may be difficult for a consumer health information worker who does not have professional health care training and experience to identify all the factors (such as co-morbidities, or currently used medications) which might be relevant in a particular case. For example, beta-blockers are an effective treatment for most people who have had a heart attack, but if given to people with asthma they can trigger potentially fatal asthma attacks. This is not something that consumer health information providers would necessarily know, so when discussing the information needs of someone who has had a heart attack they might understandably omit to ask whether or not they had asthma.[5]

Consumer health information providers might also encounter problems if enquirers are not sure what is wrong with them, because they are not in a position to make a diagnosis. Their best course of action in such cases will probably be to recommend that any

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[5] Lack of knowledge of possible reasons why a particular treatment might be inappropriate for a particular person becomes more of a problem when using research based information published in journal articles. Academic journal articles, unlike the introductory reference materials which consumer health information providers might be accustomed to, do not tend to recap basic information which is not of direct relevance to the research question being addressed. A research paper reporting on a trial to compare the effectiveness of two makes of beta-blocker might note that people with asthma, possibly along with women and people above a certain age, had been excluded from the trial, but would not necessarily explain why.

enquirers who fall into this category (assuming they are seeking information which they want to use to make a decision about their health care) consult a health professional.

Helping enquirers formulate a clear question might in itself be a valuable service offered by consumer health information providers. People often need assistance to work out the questions which they want to ask of the health professionals involved in their care.

3.5 Searching the literature – strategy A

The next step after formulating a specific question is to carry out a literature search to identify relevant research information. Strategy A involves searching bibliographic databases and/or journals for information about the patients, interventions and outcomes of interest. The basic techniques of literature searching are beyond the scope of this book, but a few useful texts are listed at the end of this chapter. One of the main differences which the focus on evidence-based health care has made to literature searching is that searches now attempt to identify not only journal articles about a particular health condition or health care intervention, but also those journal articles which provide good quality research evidence about their effectiveness. Searches thus tend to focus on particular research methodologies (e.g. systematic reviews and randomised controlled trials) as well as particular health topics in order to filter out information based on opinion or very weak evidence (see Dickersin *et al.*, 1994).

Medline remains the standard bibliographic database for general medical information, and its indexing has recently been improved so that randomised controlled trials and systematic reviews can be more reliably identified. Access to an up-to-date version of the Medline database is probably a minimum requirement for a literature search for primary research reports about health care effectiveness. Consumer health information services might need to explore the possibility of links with local medical libraries and other institutions to facilitate access to this and other major bibliographic sources such as EMBASE, CINAHL and Psychlit.[6] Consumer health information staff who intend to adopt strategy A might also need to develop their literature-searching skills to enable them to identify relevant methodologically rigorous information among bibliographic references (McKibbon *et al.*, 1993).

Medline and other bibliographic databases help identify references to relevant journal articles. Although bibliographic databases provide summary abstracts for many of the articles they index, they leave the user in the position of having to locate and retrieve copies of the relevant articles. This might be difficult for consumer health information services, which tend not to have large journal holdings. Again, access to larger medical libraries is important.

The research reports which are retrieved from literature searches are likely to be of variable quality and critical appraisal techniques are needed to assess their quality.

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[6] EMBASE (Excerpta Medica database) indexes biomedical literature. Its coverage overlaps to a large extent with that of Medline, but it has a European, rather than a US base and focus. CINAHL is the Cumulative Index to Nursing and Allied Health Literature. Pscyhlit is the electronic form of Psychological Abstracts.

3.6 Critical appraisal – strategy A

Critical appraisal is a means of assessing the usefulness and validity of the information for a particular question or decision. It is important because not all of the evidence on a particular topic is of the same quality. Critical appraisal involves consideration of:

- whether the research has been conducted in such a way that it is likely to give an accurate answer to a clear question;
- the relevance of the research to the question to be answered or the decision to be made;
- what the results actually mean (how they might be interpreted).

Basic critical appraisal skills can be learned fairly quickly by people who have no formal training in health care or research methodology, so there is no reason why consumer health information providers cannot learn how to critically appraise information about health care effectiveness (Milne & Oliver, 1996). However, it is not clear what level of competence in critical appraisal should be considered desirable among people who will use this strategy to provide information about heath care effectiveness to consumers. The game of chess may provide a salutary analogy here: it is easy to learn the basic moves which each piece can make, but it is not quite such a straightforward matter to play the game well.

The addresses of several organisations which run training sessions on critical appraisal skills are given at the end of this chapter. In the next few sections, we introduce some of the key features which should be considered when critically appraising randomised controlled trials and systematic reviews.

3.6.1 Assessing the relevance of the trial and review results to a particular enquiry

There are two basic questions which can be asked to assess the relevance of a trial or review to a particular enquiry which an individual has made about their treatment:

- Is the patient to whom the enquiry relates similar to the patients who were included in the trial or review? For example, if a drug trial included only men between the ages of 18 and 60 who were taking no other medication, the results might not accurately describe the likely effects of the drug on a 70-year-old diabetic woman who received daily insulin.
- Does the trial or review assess outcomes which the patient would want to take into account before making a decision?

If the answer to either of these questions is 'no', then there is not much point in continuing with a critical appraisal of the article: a more relevant report should be sought. However, if no research has been conducted among the population of interest, theoretical considerations might be used to provide a best estimate of the likely implications of the available research for the particular patient.

3.6.2 Critical appraisal of randomised controlled trials

Randomised controlled trials are designed to allow the effects of two interventions (or one intervention and a placebo) to be compared. A critical appraisal of a randomised controlled trial would try to assess:

- the extent to which the experimental and control groups were similar at the start of the trial and were treated similarly in all respects except for the intervention being tested;
- how likely it was that any differences between the two groups occurred just by chance (how confident we can be that any difference between the two groups was really due to the different interventions they were given).

Some key indicators of the quality of randomised controlled trials are given in Fig. 1.

Process of random allocation

If people are allocated to the experimental and intervention groups by a process which is truly random, this helps to ensure the two groups will be as similar as possible. Procedures such as assigning people to one of the two groups on the basis of their date of birth or the date of their clinic visit are not truly random and should be viewed with more caution.

Blinding

If neither health professionals, patients nor researchers know whether a patient is in the experimental or control group (for example, if two drugs which are being compared are made up into identical looking tablets), then it is less likely that the results will be biased by any prior expectations about the effectiveness of the interventions being tested. If a researcher thought that one treatment was probably better than the other, and knew which patients had received that treatment, she might be biased in her judgements and might tend to see greater improvements in those patients who received the treatment she thought was better.

Follow-up

It is important that outcomes are recorded for all the people who entered the trial because people may be more likely to drop out of a study if they suffer adverse effects from the interventions being tested, or if they find the intervention unacceptable. It is usually best if results are presented on the basis of 'intention to treat' analysis, which means that all outcomes, including drop-out, are included when examining the effect of an intervention.

Contamination

It is important to check that members of the control group did not receive the experimental intervention and vice versa so that the results are not confused.

Study size

As a general rule, the bigger the study, the less likely it will be that the results were achieved by chance.

Fig. 1 Key indicators of the quality of randomised controlled trials

It is important to note that different randomised controlled trials of the same intervention might produce different results, particularly if they did not involve many patients.

3.6.3 Critical appraisal of systematic reviews

Systematic reviews aim to provide an unbiased summary of all the available research which addresses a particular question. Those reviews which are kept up to date by incorporating data from new research as it appears can provide the best available evidence on a particular topic. However, systematic reviews can vary in their quality and should be subject to critical appraisal like any other research. Some key features of good quality systematic reviews which a critical appraisal would look for are listed in Fig. 2.

- The question addressed should be clearly and explicitly stated.
- The literature search should be comprehensive and systematic in order to identify as many relevant studies as possible. It should be well documented so that readers can assess its quality.
- The criteria used to decide whether or not individual studies are to be included in the review should be clearly stated. This reduces the likelihood of bias creeping in and should prevent reviewers from giving preference to those studies which best support their own ideas.
- The methodological quality of the included studies should be assessed.
- Possible reasons for any differences between the results of individual studies should be explored.
- It should be clearly stated exactly what data were extracted from individual studies.
- Decisions about the inclusion of studies, quality assessment and data extraction should have been checked by more than one person.
- The findings of the included studies should be appropriately combined. Quantitative synthesis, or meta-analysis, may be appropriate if the studies measured similar outcomes.
- The reviewers' conclusions should be supported by the evidence they cite.

Fig. 2 Key features of good quality systematic reviews

Several more detailed checklists have been published for use by those who wish to critically appraise studies of the effectiveness of different health care interventions. A few of these are listed at the end of the chapter.

3.7 Locating information sources which are explicitly geared towards supporting evidence-based approaches to health care – strategy B

Strategy B focuses on sources in which a certain level of quality of evidence is assured and a certain amount of guidance in interpretation is provided. These sources include:

- databases of good quality systematic reviews (e.g. *Cochrane Database of Systematic Reviews*);
- secondary publications which employ methodological quality filters and which possibly include a critical commentary (e.g. *ACP Journal Club*);
- publications and bulletins intended to provide unbiased research-based information in an accessible form to health care professionals, managers, or (more rarely) patients (e.g. *Effective Health Care* bulletins).

Some key sources of information about health care effectiveness which are geared towards evidence-based health care are described in Chapter 6 and will therefore not be discussed further here.

Strategy B still requires a certain amount of critical appraisal to assess the relevance of the information retrieved to the patient/enquirer in question. However, it may make the task of searching for relevant literature more manageable and it relieves the consumer health information provider of much of the burden of methodological assessment.

3.8 The relative merits of strategy A and strategy B for consumer health information providers

Table 1 summarises the skills and resource requirements of strategies A and B, and highlights their possible advantages and disadvantages for consumer health information providers.

Table 1 Comparison of the requirements and merits of strategies A and B

Strategy A	*Strategy B*
Need access to Medline.	Need access to specialised sources, including computer databases, journals and bulletins.
Need skills to search Medline, including the ability to search for particular study designs as well as particular topics.	Need skills to search a variety of sources effectively: the search software and indexes of the specialised sources vary.
Need to be able to access a wide range of medical journals to retrieve documents identified via Medline.	Most of the specialised sources contain either the full text or detailed structured abstracts of the relevant systematic reviews or randomised controlled trials: the essential information is identified along with the reference.
Inter-library loans may take time to arrive.	
The user must assess the relevance of the information to the particular enquiry and must have the skills to critically appraise the information to assess the adequacy of the methodology and the validity and reliability of the reported results.	The user must assess the relevance of the information to the particular enquiry, but the adequacy of the methodology is either assured or has already been critically commented on.
Critical appraisal can be time-consuming, and getting beyond the basics may be difficult.	
Medline and medical journals make few concessions to non-medical personnel: users must negotiate all the jargon.	Some of these sources are written for people without specialist medical training, but they may be less comprehensive and may not include all the methodological details. Advice about the interpretation and use of the information and commentaries on the implications of the reported findings for practice are often included.
There is more likelihood of finding some information directly relevant to the question, although the quality of the evidence is not assured.	The range of questions which can be answered directly from sources which have focused on the best quality evidence is currently limited, although it is continually expanding.

On balance, it seems that strategy B is a more manageable and appropriate approach for consumer health information providers to adopt, and should be recommended at least as a more pragmatic initial strategy. A high level of critical appraisal skills, including the ability to assess the nuances of research methods, is likely to be needed if strategy A is to be implemented to a satisfactory standard. If high quality systematic reviews or randomised controlled trials relevant to the enquiry cannot be found in the specialised 'evidence-based' sources, then recourse may be made to Medline and critical appraisal techniques will need to be applied.

3.9 Interpreting and using the evidence – providing the best information

The last step in an evidence-based approach to health care which we will consider is common to strategy A and strategy B. In clinical settings, the last step involves making a decision which takes into account the evidence about the effectiveness of the different care options. This is not a step which consumer health information providers would normally be directly involved in, but it is one of which they should be aware. One aspect of the quality of information provision is its appropriateness and usefulness for decision making. It is obviously important that enquirers should be able to understand the information they are given. Original research reports will rarely be suitable. In addition, consumer health information providers should take into account the way in which the information they provide might be used. The presentation of information is discussed further in Chapter 5.

One criticism which has sometimes been made of the proponents of evidence-based health care is that they have not always made it clear exactly *how* research evidence of health care effectiveness should be taken into account in clinical decision making. It is often assumed that a rational approach to decision making, based on combining research evidence of the probabilities of different outcomes occurring with particular interventions with the strength of patients' preferences for those different outcomes, is most likely to leave the patient with the outcomes they most desire. However, many of the scenarios used to illustrate an evidence-based approach to health care do not incorporate a structured rational approach.

Many of the proponents of evidence-based health care do argue that patients' preferences should be incorporated into clinical decisions. Some even suggest that patients should be given the research evidence and then make the decision themselves. An evidence-based approach to health care may encourage greater attention to patients' preferences, but we should be aware of tensions which may arise if patients, after considering what is known about the effectiveness of different options, still prefer the one which according to certain criteria is not the most effective.

The best available research evidence about the effectiveness of health care interventions doesn't always make decisions about health care simple! Some of the difficulties of applying it are highlighted in Fig. 3.

- There might not be enough good research to allow us to answer a particular question with any degree of confidence. The best available research evidence will often not remove our uncertainties about particular health care options.
- Research evidence usually describes the average effects of interventions among a group of people. It may tell us the *chances* that an individual who opts for a particular intervention will experience particular outcomes, but it *cannot guarantee* their preferred outcome.
- Research evidence describes the average effects of interventions across those types of patients and settings which have been included in trials of effectiveness. Sometimes, such average effectiveness data will not be a particularly good reflection of the range of possible outcomes in a particular setting. For example:
  - a patient might have particular characteristics which make certain options more risky for them than for the people included in the trials of effectiveness. The average does not really apply to them. We know some of the characteristics which predict poor outcomes, but not all of them.
  - surgeons at a local hospital might be relatively inexperienced in performing a particular type of intervention, such as laparoscopic surgery. The outcomes they achieve might therefore not be as good as those reported in studies which assessed the outcomes achieved by surgeons who were highly trained and had plenty of experience of performing this type of surgery.
- Most health care interventions cause some harm and some good. Decisions thus involve trade-offs between the advantages and disadvantages of different options.
- People might not want decisions about their treatment to be made solely on the basis of information about a narrow range of outcome measures. For example, they might also want to take into account the local availability of the different options, and the timescale of treatment and recovery. For religious or other reasons some people want to avoid certain interventions because of the processes involved.
- People may vary in their preferences for particular outcomes and their attitudes to risk. Both affect the way decisions need to be made.
- Information about the *distribution* of health care outcomes might be interpreted differently from individual and population perspectives. People making policy decisions about what health care to purchase for a population might tend to make different use of information than doctors and patients making decisions about the treatment of an individual.

Fig. 3 Issues in the use of research evidence in decision making

We suggest that consumer health information providers have an important role to play in educating (or at least informing) enquirers about some of the caveats which apply to the interpretation and use of the information they have provided (see section 5.5 for practical suggestions). They cannot do this without a good understanding of the limitations of even the best quality evidence about health care effectiveness and the types of decision it may be used to inform.

KEY POINTS

- Consumer health information providers who want to provide information about health care effectiveness should be able to provide information which accurately reflects the best available research evidence.
- If there are no suitable research-based patient information materials available, the recommended strategy for an evidence-based approach to consumer health information provision involves:
  - formulating an appropriate question
  - searching for relevant information in databases, journals or bulletins which include only high quality systematic reviews, randomised controlled trials or the best available evidence, and which have critical appraisal built in to their production process
  - providing the best available information, along with guidance about its use.
- The best available research evidence about the effectiveness of health care interventions doesn't always make decisions about health care simple!

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Further reading

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Critical appraisal skills training

Critical appraisal skills training sessions are organised by:

Institute of Health Sciences
Critical Appraisal Skills Programme
PO Box 777
Oxford OX3 7LF
Tel: 01865 226968

NTRAG
Department of Epidemiology and Medical Statistics
London Hospital Medical College
Queen Mary Westfield
Mile End Road
London E1 4NS
Tel: 0171 982 6328

Trent Institute for Health Services Research
Regent Court
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Sheffield S1 4DA
Tel: 0114 282 5454

Chapter 4

Giving research information about health care effectiveness to consumers
1: Motives, effects and responsibilities

This chapter briefly considers the diverse types of health related information and the pattern of consumer health information provision in the UK before focusing on reasons behind the current interest in providing people with research-based information about health care effectiveness. It examines the possible effects of sharing information about health care outcomes with consumers and briefly considers the roles of clinical health professionals and consumer health information services in providing such information.

➪ OBJECTIVES FOR THIS CHAPTER

When you have read this chapter we hope that you will be able to:

- recognise that there are many different types of information about health and health care, but that despite developments in consumer health information provision, research-based information about the effectiveness of health care options has only rarely been given to patients and the general public;
- be familiar with the arguments in favour of sharing research-based information about health care effectiveness with consumers;
- be aware of some of the possible effects of providing research-based information about the effectiveness of health care interventions to consumers;
- realise that information may have a different impact when provided by a consumer health information service than when provided by a health professional as an integral part of a care process.

4.1 Health information needs

There are many different types of information about health and health care relating, for example, to:

- body structures (anatomy);
- how the body works (physiology);
- causes of ill health (aetiology), including the effects of genetic make-up, lifestyle and environment on health;
- the disease processes associated with a particular condition (pathology);
- interventions used to help prevent, diagnose or treat particular conditions:
  - the processes involved (procedural information)
  - what it's like to experience it (sensory information)
  - the outcomes likely to be achieved (effectiveness information);

- the availability of particular interventions;
- the performance of health care providers (process and outcomes information);
- how you can help yourself to stay healthy or cope with an illness (health promotion and self-help information);
- costs of health care;
- voluntary organisations and self-help groups which offer help and support.

Different types of health information serve different purposes, and people's information needs vary over time. For example, basic information about anatomy and pathology might help people understand what is wrong with them and facilitate communication with their doctor. Information about surgical procedures and what to expect during a hospital stay can help people cope when they are admitted to hospital for an operation. Information about self-help groups might be particularly welcomed by people newly diagnosed as having a chronic health problem, who might also need detailed information about self-care procedures, such as administration of insulin.

Information about different health care options and what research has shown about their effectiveness is considered particularly important for people making decisions about which health care interventions they want to accept. It may help people to obtain health care which is effective and appropriate to their need. These and other uses of research-based information about health care outcomes are discussed further in section 4.3.

4.2 Patterns of consumer health information provision

In recent decades, the provision of health information to patients and the wider public has received much attention. Enormous numbers of books, articles and leaflets on health topics have been produced for lay audiences, and a wide variety of consumer health information services have come into being. Many consumer health information services were started by local enthusiasts who developed existing services in various ways from the late 1970s onwards. Hospital medical libraries extended their services to patients, public libraries strengthened their ability to provide health information-related enquiries and health information shops were set up, often as part of collaborative ventures (Gann, 1991). Specialist information services, devoted to particular issues, have grown up in conjunction with the flourishing of self-help groups. This diversity tends to mean that different consumer health information services have different strengths and weaknesses.

In 1992, as a development of the *Patient's Charter* initiative, the Department of Health required all Regional Health Authorities to set up general consumer health information services for the populations they served. In 1993 a national freefone telephone number was set up so that people can now make a free call, which is automatically routed to the nearest health information service which is part of the system, to ask for information about health and health care issues.

As consumer health information services proliferated and developed, the novelty and excitement that health information was being made available at all wore off, and concern started to be expressed about the range and quality of the information which was being provided. It is increasingly recognised that to date, much of the information given to people who find themselves on the receiving end of health care has focused on health care processes rather than health care outcomes (Gann, 1994). It describes what is done to people rather than what benefits or harms they might experience as a result. Much patient information can be characterised as providing people with the details of the mechanics of their health problem, a description of what the doctor has decided will be done to them, and some instructions which they should follow if they want to be a good patient. Information about the different health care options available for a particular condition and evidence about their effectiveness has rarely been given to people, particularly by health care providers. A few examples of projects to develop and evaluate information packages for patients about treatment options and their likely outcomes are given in Chapter 6.

In 1995, a health service guidance letter was issued (NHS Executive, 1995) which recommended that health information services which use the national freefone telephone number should be able to provide information about clinical effectiveness from April 1996.

4.3 Why give people information about health care outcomes?

Two main movements or policy thrusts in health care – the promotion of evidence-based health care and the promotion of patient involvement in decision making – have stimulated interest in the provision of information about health care options and evidence about their outcomes to patients and the public (Hope, 1996). An evidence-based approach to health care attaches great importance to an explicit consideration of the possible outcomes of health care interventions and to ensuring that the health care delivered is both effective and appropriate to individual need. It may thus encourage greater attention to the values which individual patients attach to particular outcomes. As mentioned in section 2.4.2, some advocates of evidence-based health care hope that by informing people about the effectiveness of different health care interventions, they can encourage them to demand the most effective forms of health care and thus exert a positive influence on the clinical behaviour of health professionals.

In recent years, interest in patient involvement in decision making has increased for a variety of reasons. Many people assume that when a health professional recommends a particular treatment, the advice is based on a clear understanding of individual needs and careful consideration of the benefits and risks of the treatment. People tend to be confident (or at least extremely hopeful) that the health professional (particularly the doctor) knows best. Such confidence is not always entirely justified. Firstly, for reasons outlined in Chapter 2, doctors' knowledge about the benefits and risks of many treatments may be limited. Secondly, doctors may not be aware of what the individual patient's values and priorities are, of what they most want treatment to achieve for them, or of their attitudes to risk. Arguably, without knowing an individual patient's preferences, the doctor cannot know what is best for them.

Decisions between health care interventions usually involve trade-offs between different risks and benefits. Since people may place different values on different possible outcomes, they might prefer different treatments, even if they have the same condition. When treatment options were discussed by a group of women with menstrual disorders, some wanted to avoid hysterectomy because they wanted to retain the possibility of having children, while others wanted a hysterectomy because it offered a once-and-for-all solution to their bleeding problems (Coulter, Peto & Doll, 1994). Similarly, as described in Chapter 1, some men with benign prostatic disease are keen to have surgery because it offers them a chance of relieving their symptoms, while others are less keen to have surgery because they do not want to risk the possible adverse effects on sexual functioning which it carries.

If the primary aim of health care is to improve the quality of life of the person to whom the care is being given, then it can be argued that the attitudes of that person towards the risks and benefits of the different options, and the values which that person attaches to the possible outcomes, should be taken into account when making decisions. The most obvious way to ensure that individuals' values are reflected in decisions about treatments is to involve them in those decisions. However, if they are to participate in a meaningful way in the decision-making process, they will obviously need relevant information, including information about the likely outcomes of the different treatment options.

Other motives for providing research-based information about the effectiveness of health care options to patients include the following.

- To satisfy consumer rights to information.
- To fulfil the moral and legal imperatives of informed consent.
- To discourage people from demanding ineffective forms of health care (and thus reduce wastage of health care resources).
- To help ensure that people 'comply' appropriately with recommendations about effective health care made by health professionals.
- To increase patient satisfaction (with information, care and outcomes) and to reduce the number of complaints and legal actions taken against health professionals.

It is widely hoped that the provision of information about health care effectiveness to lay people and the promotion of shared decision making (in which decisions are made jointly by health professionals and patients) may serve to improve health outcomes. This might be achieved via the delivery of more effective forms of health care, or more directly from the process of shared decision making *if* that process itself has a positive effect on health.

We stress that the effects of sharing information about health care outcomes with consumers have not been well studied and the effects of encouraging their involvement in decision making are as yet poorly understood. Many of the hoped-for effects of informed patient choice have not yet been demonstrated in the context of rigorous evaluations.

4.3.1 UK health care policy

UK health care policy is currently promoting the provision of information about treatment options and their effectiveness to patients and the enhancement of patient choice in health care. *The Patient's Charter* states that patients have a right:

> *to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment. (Department of Health, 1991)*

The Patient's Charter for Scotland states that people have a right, if they want, to accurate, relevant and understandable explanations of:

> – *what is wrong*
> – *what the implications are*
> – *what can be done*
> – *what the treatment is likely to involve*
> – *and, if they wish, a second opinion. (Scottish Office, 1991)*

One of the stated objectives for the NHS for 1996/97 is that:

> *Purchasers and providers should be able to demonstrate that they have a systematic programme in place aimed at achieving active partnership with individual patients in their own care, in particular seeking to improve the quantity and quality of information given to enable patient choice about treatment options. (NHS Executive, 1995)*

That official policy instructs it is obviously now another reason for providing people with information about health care options and what is known about their effectiveness.

The Patient Partnership strategy, launched by the NHS Executive in 1996, confirmed the policy commitment to enabling patients to become informed about their treatment and care and to make informed decisions and choices about it if they wish. At a local level, it encouraged health authorities to ensure that local Health Information Services meet and where possible exceed the specifications laid down in previous health service guidance. At a national level, further support for and monitoring of the Health Information Service was promised, as was a new resource to facilitate the production of 'patient information'.

4.4 Do people want information about the effectiveness of health care interventions?

Patients have not traditionally been encouraged to expect to be given information about health care options and what is known about their effectiveness, but there are various indications that a significant proportion of people now want it. Surveys consistently show that a majority of people want information (and more information) about their health and health care, and that many people are dissatisfied with the information they receive from health professionals (Audit Commission, 1993). It seems that many patients do need/want information about the possible as well as the probable implications of particular health conditions and treatments (Meredith *et al.*, 1995).

Patient representatives generally believe that research-based information about health care effectiveness should be readily available. A recent workshop of patients' organisations reached consensus on six general principles for giving information to patients. One of these was:

> *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.* (*Anon.*, 1995)

A recent survey of UK consumer health information services found that most of them reported receiving enquiries relating to treatment choices from members of the public. An enquiry monitoring exercise showed that, on average, 18 per cent of enquiries related to treatment options and that some of these were made at a time when the information supplied could be used to influence decisions about treatment (Gann & Buckland, 1994).

However, we should remember that not all people want information about health care options and their effectiveness, and also that not all of those who want it want to use it in any particular way. Several surveys suggest that people may want more information even if they do not want to participate in decision making about their treatment (Silverstein *et al.*, 1991).

4.5 The effects of information provision

The provision of information about health care options and outcomes via consumer health information services can be regarded as a health care intervention in its own right which should be subject to evaluation like other health care interventions. It is important that the effects of different ways of providing information about health care effectiveness are investigated.

There have been quite a few studies of the effects of giving people information about their own condition and about health care procedures. Researchers have tended to focus on three areas: the provision of information to enhance compliance with medical recommendations; the provision of information to people with chronic diseases such as asthma and diabetes to encourage and facilitate self-management; and the provision of information to people about to undergo surgery or invasive medical procedures to assist with coping processes. Speaking very generally, people who have been given information in such contexts have tended to do better, in some cases in terms of measured health outcomes, than those who have not (Kempson, 1987; Suls & Wan, 1989).

However, providing basic information about a health condition, together with procedural information about a treatment which a person knows they will be given, is not the same as offering information about the risks, benefits and outcomes of all the treatment options available before a decision about the treatment of choice has been made. It is not known what the effects of giving information about health care options and their likely outcomes will be. They may vary from person to person, and are likely to be influenced by the nature of the professional-patient relationship, the patient's health condition and psychological characteristics, and the nature of the 'message' about the options for care and their probable outcomes (Entwistle *et al.*, 1996).

Most studies of the impact of health information provision to patients and potential patients have examined the effects of information/educational interventions given by health care providers as part of the care process, rather than by consumer health information services. Information provided by a consumer health information service is introduced into health care decision-making processes in a different way, and might thus have a different impact. This is discussed further below.

The provision of information about health care options and their effectiveness might affect a variety of outcomes, including the following.

- Knowledge about specific treatment options and their effectiveness.
- Understanding about health care effectiveness in general.
- Preferences and expectations relating to levels of involvement in decision making, relationships with health care professionals, health care and health care outcomes.
- Professional–patient relationships.
- Processes of health care decision making.
- Health care decisions made, and the extent to which patients feel comfortable with these decisions.
- Patterns of health care delivered.
- Health status, including psychological well-being.
- Perceptions of health care (including satisfaction with various processes and outcomes of care).

Little is known about the actual effects of providing information about the effectiveness of different treatment options to consumers. Research is needed to investigate the actual rather than the hypothetical impact of the provision of such information, and to explore whether different ways of providing the information give rise to different effects.

4.6 The roles of health professionals and consumer health information services

The Patient's Charter and other policy documents have made it clear that people have a right to receive information about treatment alternatives and evidence for their effectiveness, but have been less clear about whose responsibility it is to provide the information.

Proponents of shared decision making often envisage an ideal situation in which health care professionals have the inclination, the skills and the time to ascertain how much information and how much involvement in decisions about their health care individual patients want, to discuss all the available options with them, to provide them with outcomes information based on the best available research evidence, and to support them in a shared decision-making process. In practice, many interactions between health professionals and their patients do not match this ideal. Reasons for this include the following.

- Patients may not expect to play an active role in decision making, and indeed may prefer not to. Some health professionals may prefer to retain full control over clinical decision making.
- Health professionals may be unable or unwilling to provide information about all the relevant treatment options and the research evidence of their effectiveness. Some conditions may be treated by a variety of different health professionals who do not all know about each other's treatment approaches, and who may have a vested interest in promoting their own. For example, back pain may be treated by general practitioners, orthopaedic surgeons, osteopaths, chiropractors and physiotherapists; cancers may be treated by general surgeons, oncologists (doctors specialising in the treatment of cancers), radiotherapists, and so on.
- Patients may not be able to process relatively complex information, to identify and express their own preferences, and to negotiate effectively with health professionals.
- Health professionals may lack the inclination or the ability to facilitate effective patient involvement in the decision-making process.
- Features of health care organisation, such as pressures on consultation times and the lack of continuity of care, may discourage the necessary information exchanges and interactions between health professionals and patients.
- There are currently few information packages available to supplement verbal information provided by health professionals and to facilitate informed patient participation in decision making.

Consumer health information services which provide a confidential service may be particularly useful for people who want health information but find it difficult to get it from their health care professionals. Consumer health information services respond to people at the point at which they ask for information. This implies that they are well placed to give information to people at the times when they most need/want it. Consumer health information workers might be less likely than health professionals to have strong biases in favour of particular treatments or clinical specialties. However, they are not always so well placed as health care professionals to provide information about treatment effectiveness which applies well to individual enquirers. As discussed in section 3.4, they rely heavily on the information which enquirers give them about their diagnoses, and in the absence of clinical training may not be able to identify all the factors which need to be considered in a particular treatment decision. Thus their ability to ascertain the applicability of research-based information about health care effectiveness to particular individuals may be limited.

Consumer health information providers are not usually an integral part of the health care teams treating an individual and do not usually get involved in individual treatment decisions. They have no control over how the information they provide is interpreted and used,[1] and cannot guarantee that everyone to whom they supply

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[1] Concern about the potential for information provided by consumer health information services to be used in a way which may lead to the patient being harmed highlights the importance of the issue of liability, which is discussed in Chapter 5.

information will be able to discuss it with sympathetic health professionals. People who introduce information they have received from a consumer health information service into a consultation with a health professional may meet with varying responses. Consider, for example, the following two scenarios.

- In a recent consultation, the doctor diagnosed condition X and told the patient there were three different treatment options: A (an operation), B (a different operation) and C (a drug). The doctor described the different options and their implications and suggested that the patient thought them through before the next consultation when they could decide together how to proceed. The patient left the consultation and telephoned the information service because she wanted more detailed information about the three options, preferably in a written form.
- In a recent consultation, the doctor diagnosed condition X and told the patient he would perform operation A to sort it out. The patient was sent an appointment card for admission to hospital in a few weeks' time, but was uncomfortable about the prospect of surgery and called the information service wanting to know if there were any other treatments available.

The doctor-patient relationships underlying these two scenarios are quite different, and one suspects they would be differently affected should the patient tell the doctor that she had obtained information about options A, B and C from a consumer health information service. The impact of information provided by consumer health information services and the relationships between consumer health information services and health care professionals warrant careful consideration.

As yet we know relatively little about how enquirers use the information they receive from consumer health information services. A US study showed that just under half of the callers to a specialised cancer information service discussed the information they were given with their physician. In many cases the physician already had the information. Some physicians did something positive to follow up on the information, while others reacted negatively either to the fact that the patient had sought the information from a third party or to the information itself (Manfredi *et al.*, 1993). It is not clear to what extent these findings reflect the use which is made of information provided by general consumer health information services in the UK.

The roles of health professionals and consumer health information services in sharing information about the effectiveness of interventions with patients and the public would ideally be complementary. If both are providing information which accurately reflects the best available research evidence of health care effectiveness, then both should be providing consistent information. The best kind of complementarity, however, is likely to require a certain amount of co-ordination between the two. For example, if health professionals know what information the local consumer health information service can provide about particular conditions, they might suggest to their patients that they contact the local consumer health information service for further information, allowing both health professionals and patients to focus on the essential points more quickly during a consultation.

KEY POINTS

- To date, research evidence about the effectiveness of different health care options has rarely been given to patients, either by health professionals or consumer health information services.
- The promotion of evidence-based health care and the promotion of patient choice have stimulated interest in the provision of research evidence about the effectiveness of relevant health care options to patients.
- Motives for providing information about the effectiveness of relevant health care options include: respect for individual rights to information and choice; to facilitate patient participation in health care decision making; to encourage people to demand effective and appropriate forms of health care; and to improve health outcomes.
- There are currently very few information packages for patients which provide research-based information about the effectiveness of treatment options.
- Little is known about the effects of providing research information about the effectiveness of different health care options to consumers.
- Health professionals and consumer health information providers have different strengths and weaknesses when it comes to providing research information about the effectiveness of those health care options relevant to patients. Consumer health information services might be better placed to provide an unbiased overview of all the options, while health professionals will usually be better placed to understand how generally available information applies to an individual patient.

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Chapter 5

Giving research information about health care effectiveness to consumers
2: Practical considerations, quality and liability

This chapter considers some of the practicalities involved in the provision of research-based information about health care effectiveness to consumers. It explores the factors which might affect the quality of information packages intended to help people make choices about treatments, paying particular attention to those aspects of presentation which influence the way information is understood. It also highlights some of the ethical and legal issues raised by the provision of information about treatment effectiveness by consumer health information services.

➩ OBJECTIVES FOR THIS CHAPTER

When you have read this chapter we hope that you will be able to:

- realise that research-based information about health care effectiveness is not yet widely available in formats appropriate for consumers;
- realise that substantial skills and resources are required to produce information packages to support consumer involvement in decision making;
- be aware of some of the factors which contribute to the usefulness of an information package for consumers about health care effectiveness;
- realise that the manner in which research-based information about health care effectiveness is presented may affect the way people understand and use it;
- understand the basic issues of liability which affect consumer health information provision, and know how consumer health information providers can minimise their risks.

5.1 A major challenge

Recent health service guidelines on the provision of the national freefone health information service stated that:

> *As a minimum HIS [Health Information Services] will be required to provide information to callers on the following: ...* Outcomes and effectiveness data: *Available researched/evidence-based information should be provided in appropriate formats to enable users to make informed choices between treatment options.* (NHS Executive, 1995)

This is a major challenge, as we will discuss below. The guidelines go on to suggest that:

> *This information should be used in conjunction with advice from the user's own GP. Typical information sources will be* Effective Health Care *bulletins, the* Cochrane Database of Systematic Reviews *and the NHS Centre for Reviews and Dissemination.*
> *(NHS Executive, 1995)*

A variety of enquiries, ranging from a straightforward question about whether the minor symptoms which a person has experienced since starting to take a particular drug are likely to be side-effects of that drug, to a request for 'all the information you've got' about different treatments for a particular condition, might require consumer health information providers to supply research-based information about health care outcomes and effectiveness. Different types of enquiry require different types of response. While a brief verbal answer might be an adequate response to a very specific question, the provision of written (or other recorded) information is usually desirable, particularly if it may influence decisions about treatment, because most people can only recall a small proportion of verbal information accurately, even soon after they have been given it.

Common sense dictates that research evidence about treatment effectiveness generally needs to be presented to consumers in a more concise way and using less technical language than is seen in the traditional research reports which mark its entry into the 'public domain'. However, it is not obvious which are the most appropriate formats for presenting such information, and there have been few evaluations which compare the effects of providing such information via different means. Simple summaries of the findings of a particular randomised controlled trial or systematic review and comprehensive information packages, including structured decision aids to support people facing specific decisions between treatment options might both be useful in different circumstances. Basic information leaflets and sophisticated interactive videodisc programmes both have advantages and disadvantages.

One major problem for consumer health information providers who wish to provide research-based information about health care effectiveness is that much of this information is simply not yet available in packages which make it intelligible and easily usable for the majority of consumers. This may be one reason why Gann & Buckland (1994) found that about 30 per cent of treatment enquiries handled by consumer health information services were answered in verbal form only. While some of the people who call consumer health information services might be able to understand research-based information about effectiveness as it is presented in the *Cochrane Database of Systematic Reviews* or the *Effective Health Care* bulletins, most will find these sources too technical or not clearly enough focused on their needs to be useful.

Although there are now several major initiatives to develop and evaluate information packages containing information about health care options and what is known about their effectiveness (see, for example the reference sheets in Chapter 6 about the Informed Choice initiative which provides information about care during pregnancy and childbirth, and the King's Fund Promoting Patient Choice projects which address seven common health problems), it is likely to be quite a while before research-based outcomes and effectiveness information is available 'off the shelf' in appropriate formats for patients for a significant proportion of health conditions.

In the meantime, it seems that consumer health information providers are expected to select and 'translate' information from sources such as the *Cochrane Database of Systematic Reviews* and the *Effective Health Care* bulletins into appropriate formats for their enquirers. Such selections and translations require substantial skills, both for understanding the research data and being able to extract what is relevant to the enquirer, and for communicating the information in such a way that the enquirer can understand it. They also take a lot of time. Even those consumer health information providers who have attended basic critical appraisal skills courses might understandably question their capacity to provide the best available research evidence in the most appropriate written formats on demand in response to enquiries. Additional training and resources for consumer health information providers such as that provided as part of a central support programme for the Health Information Service (Gann, 1996) may help, but the routine production of 'consumer friendly' summaries of key information sources by a specialised centralised source might provide a more acceptable and cost-effective long-term solution.

5.2 Thinking about quality

People may use the information they are given about health care effectiveness to help them make decisions about their care. Decisions, for example, about whether or not to opt for a particular surgical procedure may have a major impact on people's lives, so it seems particularly important that the information they use is of good quality. However, the question of what constitutes quality in the provision of research-based information about health care effectiveness to consumers is a complex one. Opinions about the quality of information packages are likely to vary, particularly between people who have different ideas about why information about health care effectiveness should be provided and how it should be used. Information packages with different intended audiences and purposes might need to be judged by different criteria.

We will concentrate here on the quality of information about health care effectiveness which is intended to facilitate patient involvement (with their health professionals) in decisions about their care, and to help ensure that they can choose the option which is most likely to maximise their overall well-being. If people are to get involved in decisions about their care, they must obviously be given information about the different care options in a form which they can use, and they must be given this information before a decision is made. However, it is by no means clear exactly how much information of what type(s) and in what form people need in order to participate in a shared decision-making process which is likely to result in the largest possible gain in health and well-being.

Given the current limited state of understanding about the effects of providing people with information about health care options and research evidence of their effectiveness, it is inappropriate to be prescriptive about the precise form which information packages should take (Entwistle *et al.*, 1996). However, there are several basic dimensions of quality which can be considered in relation to information to support decision making.

These include the following.

- *Relevance:* is the information which is provided relevant to the decision to be made? Is it possible to tell whether the information applies to the individual to/for whom it is provided?
- *Comprehensiveness:* is all of the important relevant information provided? If some information which would be regarded as important is simply not available, is that clearly stated?
- *Accuracy:* does the information reflect the best available research evidence of effectiveness?
- *Accessibility:* can people obtain the information easily?
- *Comprehensibility:* is the information presented in such a way that people are likely to understand it correctly?[1]
- *Acceptability:* is the whole package via which information is provided acceptable to the intended users?

Various features of the content and presentation of information packages, and of the context in which they are provided and used, will affect these dimensions of quality. We consider some of these in the following sections.

5.3 Information content

Individuals vary in their information needs and preferences. People with the same health condition who are faced with the same decision about treatment may have different information requirements. However, for practical reasons, most information packages are aimed generally at people with a particular condition. Some of the features of information content which are likely to be important in packages intended to support treatment decisions are listed in Fig. 4.

- Information is provided about all relevant treatment options
- Information is provided about all the important possible consequences (benefits and harms) of these options, and about their implications for patients.
- Information is provided about the chances of these consequences occurring.
- Information is based on the best currently available research evidence, and important gaps in research evidence are acknowledged.
- Some indication is given of the degree of certainty of the information provided.
- It is made as clear as possible to what kind of people the information about health care outcomes applies.

Fig. 4 Important features of the content of information to support treatment decisions

One particular problem for consumer health information providers who try to put together information packages which encompass all the relevant treatment options is

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[1] People vary in their ability to understand information presented in different ways, and different people may derive different meanings from the same information package.

that many of the research papers which they need to use as sources refer to just one or two of those options. It may be difficult to obtain comparable information about all the different ways of managing or treating a particular health condition.

The selection of information to include will not always be straightforward. For example, an evidence-based approach to health care emphasises the importance of research-based information about the effectiveness of interventions in clinical decision making. This implies that it is research-based statistical information about the outcomes of particular options which patients most need for decision making. While this information is important, people might also want to consider other types of information, for example about treatment processes, about the rationale underlying different treatment approaches, about whether treatments are available locally and how soon, and about recovery times. Increased attention to the provision of good quality research-based information about health care effectiveness should not detract from the provision of other important types of information. Judgements about the importance of particular aspects of information content will inevitably be subjective. However, it seems appropriate that they should be made after careful consideration of the information needs and preferences of the intended users.

5.4 Information presentation

Various features of the way in which information about health care effectiveness is structured and presented have been shown to affect the ways in which people understand and use it. These include the following.

- The order in which information is presented (Mazur & Merz, 1993).
- The different types of information which are presented together (Wills & Moore, 1994).
- The framing of messages as positive, negative or mixed[2] (O'Connor *et al.*, 1985, 1989; Siminoff & Fetting, 1989; Banks *et al.*, 1995).
- The ways in which probabilities are expressed (Malenka *et al.*, 1993; Fahey *et al.*, 1995).
- The scales and other features of graphical information (Mazur & Hickam, 1990).
- the degree of certainty implied (Eraker & Sox, 1981).

In addition, the following factors may also have an impact.

- Whether or not there is a clear statement to the effect that information is based on rigorous research and represents the best available research evidence.
- Whether or not there is an explicit statement encouraging patients to get involved in decisions about their treatment.
- The extent to which the information presented reflects the cultural background of the patient.
- The attribution of information to a particular source (Frewer & Shepherd, 1994).

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[2] Positively framed messages talk in terms of gain, survival, recovery, etc., while negatively framed messages talk in terms of loss, mortality, relapse rates, etc.

Aspects of information content, such as the levels of probability of success or failure of a particular treatment, may also interact with some of the above presentational factors to further affect how people interpret and use information.

In the next few sections, we consider two aspects of message construction, presentation of risk information and message framing, in a little more detail. We then briefly consider the way in which information is written and laid out, and the media via which it is delivered.

5.4.1 Presenting probabilities

Research-based information about the effectiveness of a health care intervention usually describes the effects observed when a group of people were given the intervention. It describes the pattern of benefits and harms seen within the group, and hence the probabilities of those benefits and harms occurring among people who are given the intervention. These probabilities can be presented in a variety of ways. For example, claims about the effectiveness of a treatment which is intended to reduce the risk of death among people with a particular form of heart disease could be phrased in the following ways:

- the risk of dying is reduced with this treatment;
- the risk of dying is reduced by a third with this treatment;
- the risk of dying is reduced by 0.05 with this treatment;
- you need on average to give 20 people this treatment in order to prevent one death.

In fact, all of the above statements could be true at the same time, although they may sound quite different and may create different impressions about the effectiveness of the treatment.

In the next section, we introduce relative risk, absolute risk and 'number needed to treat' statistics, with some information about how these are calculated. We suggest that it is more important that consumer health information providers are aware that there are different ways of presenting risk, and that these affect how people tend to understand risks, than that they can calculate the different statistics. However, an ability to represent risk information in different forms may be helpful.

5.4.2 Risk statistics: a worked example

Imagine a large randomised controlled trial to test the effectiveness of a new drug b which is intended to reduce the risk of death and of heart attacks in people with a particular form of heart disease. One thousand people with this form of heart disease (group A) were given normal treatment and a placebo drug (in this case a sugar pill). Another 1000 (group B) were given normal treatment and the new drug b. The people were followed up for five years after they started taking the drugs. At the end of five years, 150 people from group A and 100 people from group B had died, as shown overleaf.

	Alive at 5 years	Dead at 5 years	Total
Group A (placebo)	850	150	1000
Group B (drug b)	900	100	1000
Total	1750	250	2000

We can rewrite this information to show the proportions of people taking the placebo and drug b who are alive or dead at five years in decimal fraction form:

	Alive at 5 years	Dead at 5 years
Group A (placebo)	0.85	0.15
Group B (drug b)	0.90	0.10

The risk of dying among people in group A was 150/1000 or 0.15. The risk of dying among people who took the new drug b was 100/1000 or 0.10. These statistics are called *absolute risks*. The *absolute risk reduction* is the difference between the absolute risks with treatment and the absolute risks with no treatment, i.e. 0.15 – 0.10 = 0.05. Hence, 'the risk of dying is reduced by 0.05 with this treatment'.

The calculation of absolute risk reduction is an important step on the way to calculating a very useful statistic, the *number needed to treat* (NNT). The number needed to treat tells you how many people have to be given a treatment in order to achieve one positive outcome (in this case, the prevention of one death or heart attack) which would not otherwise have occurred. You can work out the number needed to treat by taking the inverse ('one over') of the absolute risk reduction. In this case, 1/0.05 = 20. Thus, for every 20 people with the particular heart condition who are given drug b, one death will be prevented. Hence, 'you need on average to give 20 people this treatment in order to prevent one death'. The number needed to treat is 20.

The *relative risk reduction* expresses the differences in the death rates between groups A and B, compared with what would have happened with no treatment (the rate among control group A). It is calculated by dividing the difference between the rates of negative outcomes in the control and experimental groups by the rate of negative outcomes in the control group.

$$\text{Relative risk reduction} = \frac{\text{Risk in group A} - \text{risk in group B}}{\text{Risk in group A}}$$

In this case, the relative risk reduction is $\frac{0.15 - 0.10}{0.15} = 0.33.$

Hence, 'the risk of dying is reduced by a third with this treatment'.

You might also come across a statistic called an *odds ratio*. This is calculated by dividing the odds of an event occurring in the experimental group by the odds of an event occurring in the control group. An odds ratio of less than one means that the event is less likely to occur in the experimental than in the control group. In our example, the odds of death in the experimental group are 100/900, or 0.11, and the odds of death in the control group are 150/850 or 0.18. The odds ratio is 0.11/0.18 = 0.63. Odds ratios are quite difficult to interpret, but they can be thought of as similar to relative risks, especially if the chances of an event occurring are quite small.

Because people understand and use risk information differently when it is presented in different ways, it may be sensible to present several statistics at the same time. Certainly relative risk reductions can be misleading if they are not accompanied by information about the absolute risk. For example, the information that the risk of a particular side effect occurring was five times greater with drug a than with drug b has different implications if the absolute risk with drug b is one in ten (0.1) than if it is one in 10,000 (0.0001).

5.4.3 An aside

In the above example, the figures suggest that *all other things being equal* it would be advisable for people with the particular heart condition discussed to take drug b, since it offers them a better chance of survival. However, all other things aren't necessarily equal. The data we have just considered do not tell us, for example, whether the people in group B suffered from more headaches than those in group A, or whether they were more likely to have non-fatal strokes which left them severely disabled. They do not tell us how expensive drug b is, and whether its widespread use would mean that other health care interventions could not be funded. This should again remind us that there can be serious limitations to good quality research-based information, even if a lot of statistics are presented.

5.4.4 Message framing

Information about treatment effects can be given in positive or negative frames, i.e. in terms of gain or in terms of loss. For example, an 85 per cent chance of survival could also be called a 15 per cent risk of dying, and a treatment which relieves symptoms in 90 per cent of cases does not relieve symptoms in 10 per cent of cases.

People are more likely to opt for treatment if treatment outcomes are expressed in terms of likely success/survival, than if they are expressed in terms of likely failure/death. O'Connor (1989) asked cancer patients and healthy volunteers to indicate their preferences for a toxic treatment (one with side-effects) over a non-toxic treatment (less effective, but with fewer side-effects) at varying probabilities of survival. Preferences for the toxic treatment were weaker when the chance of survival was less than 50 per cent, and this weakening preference was greater when the information was expressed in terms of probability of death rather than probability of survival. It has been suggested that it may be appropriate to present information to people in both positive and negative frames to avoid unduly biasing their decisions (Hope, 1996).

5.4.5 Writing style and layout

There are some commonly accepted guidelines of good practice in the production of written information for patients. These relate to writing style, use of particular typefaces, illustrations and layout, all of which tend to affect the accessibility, comprehensibility and acceptability of information packages. Some of the information which is intended for use by patients is too difficult for most of them to read because it is presented in long, technical words and complex sentences (Albert & Chadwick, 1992; Gunn, 1993). Some information is illegible because it is so poorly reproduced. Readability and presentational issues will not be discussed in detail here, but suggestions for further reading are given at the end of the chapter.

5.4.6 Communication media

A variety of media can be used to convey or repeat information, including leaflets, audio-cassette tapes, videos and interactive videodiscs. These all have advantages and disadvantages in terms of making information accessible to different audiences, being able to update research-based information when necessary, being able to deliver individually tailored information and so on. They also vary greatly in cost.

People vary in their preferences for, and willingness and ability to make use of, different media. For example, audio-cassettes are particularly suitable for people with visual impairments, and glossy magazine-style leaflets may have greater credibility among younger than older people. The effectiveness (and cost-effectiveness) of different media for use among different groups warrants careful consideration.

5.5 Guidance about the interpretation of information about effectiveness

People may need help to understand and interpret research-based information about health care effectiveness, so it is important to consider the contexts in which information packages are provided and used. Consumer health information providers have a role to play in educating people about the basic issues of health care risks and benefits and about how to interpret and use research-based information about health care effectiveness. While it is usually inappropriate for them to advise people what treatment to opt for in a particular situation, it seems desirable that they give people some guidance about how to use the information they supply.

Consumer health information services might be advised to think about developing handouts to accompany the written information they provide about treatment effectiveness to encourage people to use the information appropriately. These might take into account the points mentioned in section 3.9. Some suggestions are given in Fig. 5.

It should be remembered that not all enquiries which require the provision of outcomes or effectiveness data will be made before treatment decisions have been made or by people who want to play a more active role in the decision-making process. It may sometimes

- All treatments have risks as well as benefits.
- Different treatments have different risks and benefits. The 'best' treatment for you might depend on what benefits you most want to achieve and what risks you most want to avoid.
- It is not usually possible to *guarantee* what effect a treatment will have on you. Research into how well treatments work might tell us, for example, that nine out of ten people who have a certain treatment get better, but it cannot tell us which nine those will be.
- Average information about treatment effectiveness might not always apply to you. For example, you might have a less severe problem than the people on whom a treatment has been tested, or you might have other health problems that they didn't. These might mean that the treatment works differently in you.
- It is usually advisable to discuss the information you have been given with a health professional who knows you before you make a decision about treatment.

Fig. 5 Some points to consider when using information about health care effectiveness

be appropriate to provide information about the likely outcomes of one intervention only, rather than of all other possible options.

5.6 The production of information packages

Various aspects of the production of information packages are likely to affect their quality. Some of the production processes which *might* enhance the usefulness of a package about the treatment options for a particular condition are listed in Fig. 6. However, these features may be expensive, and it is not always possible to tell when they are essential and when they are likely to result in significant improvements to the end product.

- A prior assessment of the information needs and preferences of likely audiences
- Involvement of people who have experienced the condition as patients and health professionals in the development of materials
- Peer review of drafts by clinical and academic experts, and by 'ordinary' health professionals and representatives of the intended audience
- The use of professional writers and designers who know how to make texts readable, understandable and attractive
- The application of readability tests, plain English assessments, etc. to texts at formative stages
- Formative pilot assessments among potential users

Fig. 6 Production processes which may enhance the quality of information packages

It is also obviously important that steps are taken to ensure that information packages continue to accurately reflect the best research evidence currently available. Mechanisms need to be available to monitor new research findings and to update information packages as necessary.

5.7 Ethical and legal issues

Consumer health information services obviously have ethical responsibilities to the people to whom they provide information. They may also be liable in law for the consequences of their information giving, and while it is unlikely that a consumer health information service would be sued for negligent information giving, it is not impossible.

The standard of care in information provision which would be expected of a consumer health information service if it had to defend itself in law would be that of competent information professionals. Higher standards would be expected if a consumer health information service had made specific claims about its services. For example, a service which stated in its publicity materials that it could provide information about health care treatments, including information about the effectiveness of different treatment options, would be expected to be more capable of doing so than one which had not made such claims.

Higher standards of care in information giving are also expected when the recipient of the information is relying (and is known to be relying) on the information provided. Providing information about the effectiveness of different health care options to someone who has said they are trying to make a decision between treatments might carry a heavier responsibility than providing information about how to change a GP or about recipes for healthy eating.

The following factors are likely to increase the liability obligations of consumer health information services.

- The recipient is going to rely (reasonably) on the information s/he is provided with.
- The recipient pays money for the information.
- The information service is statutorily obliged to provide the information.
- The information service interprets information for an individual and provides advice, rather than presenting them with information and letting them read and interpret it for themselves.

This last point may create a dilemma for consumer health information providers, who are often aware that people need help to understand information about health care effectiveness. As mentioned above, it will usually be more appropriate for consumer health information services to provide general guidance as to how to interpret information than specific advice about what to do in a particular situation.

Some of the ways in which consumer health information services can protect themselves against negligence claims are listed in Fig. 7.

- **Adopt recognised good practices** (e.g. use reliable, up-to-date sources of information) and make sure that all staff are trained to follow good practice procedures.
- **Document information provision procedures.**
- **Communicate any concerns** about the reliability of an information source or a particular piece of information to the enquirer.
- **Publicise clearly what the service does and does not do.** It is important that users and potential users are made aware of what the service does and does not claim to do. They should be informed about the scope of the service's activities and the practices used. Disclaimers, for example, might state that while the information service attempts to use sources of information which are recognised as being based on reliable evidence, it cannot guarantee their correctness on every occasion. They might also state clearly that the information should be interpreted and used with care. Statements which attempt to deny all liability would not be acceptable in a court of law and are probably meaningless.
- **Take out appropriate insurance.** Professional indemnity insurance would protect a consumer health information service from serious financial loss in the event of it being required to pay damages resulting from negligent information provision. It would also mean that if someone was harmed as a result of negligent information being provided, they would be able to obtain compensation from the larger resources of an insurance company rather than the relatively small funds of a consumer health information service.

Fig. 7 Protecting a consumer health information service against negligence claims

KEY POINTS

- Research-based information about health care effectiveness is not yet widely available in formats which are appropriate for consumer use.
- Substantial skills and resources are required to 'translate' and incorporate research findings into information packages for consumers.
- The usefulness of an information package about health care effectiveness depends on a variety of features of information content and presentation, and on the context in which it is delivered and used.
- Consumer health information providers should seriously consider providing guidance about how information about health care effectiveness should be interpreted and used.
- The ethical and legal responsibilities of consumer health information providers may be increased when they provide information about health care effectiveness which is likely to be used to inform treatment decisions.
- Consumer health information services can reduce the likelihood of negligence claims being made against them by adopting and documenting good practices, publicising clearly what they do and do not do, and communicating any concerns about an information source to enquirers. Professional indemnity insurance is recommended.

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Gann R (1995) The therapeutic partnership: legal and ethical aspects of consumer health information. *Health Libraries Review*; 12:83–90.

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Chapter 6

Useful sources of information

This chapter is basically a reference guide which describes useful sources of information about health care effectiveness. Summary information sheets have been prepared about information sources which are based on good quality evidence. These information sheets describe the aims and content of each of the sources, together with brief notes on how they are produced and how they may be accessed. The information sheets have been checked by the relevant editors or producers and were correct as of October 1995.

The following types of information sources have been included.

- Databases or bulletin series of systematic reviews which have been produced using a rigorous methodology.

- Databases, journals or bulletins of secondary publication which employ methodological quality filters and thus include only reports of good quality studies (several of these sources also include critical commentaries, and some explicitly aim to make important evidence more accessible to health care decision makers).

- Independent (non-commercial, non-governmental) information sources which are produced with careful attention to available evidence and which explicitly aim to help health professionals ensure that their practice is effective and appropriate.

Very few of the information sources described are written or produced for lay audiences, although some explicitly aim to communicate clearly to non-specialist health professionals and managers. We recommend them as sources which consumer health information services might use as reference material to help staff provide accurate and reliable information about health care effectiveness in response to enquiries. Few of them will be suitable for direct consumption by the majority of enquirers to consumer health information services, but they could obviously be useful to help develop information packages which are appropriate for use by members of the public.

The sources are arranged in alphabetical order. At the end of the source guide, we also provide brief notes about the NHS Centre for Reviews and Dissemination and the Cochrane Collaboration.

This source guide does not cover the bibliographic databases, such as Medline, or primary research journals, such as the *BMJ* and *Lancet*, because these are already well known and described, and are relatively easily available through medical, or even public, library systems.

ACP Journal Club

Aims: To provide abstracts of published research which warrants immediate attention by physicians attempting to keep pace with important advances in the treatment, prevention, diagnosis, cause, prognosis or economics of the disorders which fall into the category of internal medicine.

Content: Structured abstracts of research articles published elsewhere which are relevant to general internal medicine. The abstracts are accompanied by commentaries from subject experts which put the articles in the context of preceding research, highlight any methodological problems which affect their interpretation, and makes recommendations for clinical practice. The journal also includes editorials relevant to evidence-based health care.

Production: An editorial team based at McMaster University, Canada, screens over 30 medical journals and identifies research articles of potential relevance to clinical practice. The methodological quality of relevant articles is assessed and those which meet pre-defined criteria are accepted. A structured abstract of articles which pass the quality check is written by research staff, and a commentary is provided by a subject expert. The abstract and commentary are reviewed by the author of the original paper.

Notes: See the related entry for *Evidence Based Medicine – The Journal*

Intended audience: Physicians

Format: Journal. Also available on disc (two issues per year) for IBM PC or Apple Macintosh computers.

Frequency: Bi-monthly

Produced by: McMaster University and American College of Physicians

Published by: American College of Physicians

Subscription: (1994) $50.00 per year
ACP Journal Club on disc $99 for non ACP members

Contact:

Editorial
Brian Haynes
Faculty of Health Sciences
McMaster University
1200 Main Street West
Hamilton, Ontario
L8N 3ZS Canada

Subscription
American College of Physicians
Independence Mall West
Sixth Street at Race
Philadelphia
PA 19106-1572
USA

Bandolier

Aims:	To alert readers to key pieces of evidence about health care effectiveness and to provide a signpost to primary sources; to clarify concepts relevant to evidence-based health care; to alert readers to projects, initiatives and information relevant to evidence-based health care.
Content:	Short articles which summarise and discuss important evidence, highlight initiatives or explain statistical and other concepts relevant to evidence-based health care. Full reference or contact details are provided to enable readers to obtain further information. Indexes appear in March, June, September and December issues.
Production:	Articles are either prepared by the editorial team or submitted for publication by readers. They are checked for quality and accuracy by the editorial team.
Intended audience:	Health care professionals, health service managers
Format:	8 A4 sides. Also available in electronic format from http://www.jr2.ox.ac.uk/Bandolier
Frequency:	Monthly
Produced by:	Anglia and Oxford Regional Health Authority
Published by:	Anglia and Oxford Regional Health Authority
Subscription:	Free within the NHS. Otherwise £2.50 per issue
Contact:	*Editorial and subscription* Dr RA Moore, Dr H McQuay, Dr JA Muir Gray Bandolier Editorial Office c/o Pain Relief Unit The Churchill Oxford OX3 7LJ Tel: 01865 226132 Fax: 01865 225775

Cochrane Database of Systematic Reviews

Contents: Records of structured reports of systematic reviews carried out by the Cochrane Collaboration. These include:

- Cover sheet comprising review title and citation details and contact details for the reviewer(s) and review group
- Review report, including: introduction/statement of objectives; materials and methods used; results; siscussion
- Full citations of studies included in the review, and also of potentially relevant studies which were excluded
- Table of the characteristics of the trials included in the review
- Table of the results of the review, with statistical syntheses where appropriate
- Contact details for further information about unpublished and ongoing trials

The *Cochrane Database of Systematic Reviews* is available as part of the Cochrane Library. This also includes: Titles and protocols of systematic reviews which are currently being prepared; bibliography of previously published systematic reviews; bibliography of articles on review and trial methods; information about the Cochrane Collaboration; a copy of the *CRD Database of Abstracts of Reviews of Effectiveness* (see separate entry)

Formats: Floppy disc (for IBM PC or Apple Macintosh computers), or CD-ROM.

Search software: Windows-based software. Relatively unsophisticated search options. No indexing as yet.

Potential developments: Simple definitions of statistical and epidemiological terms are being prepared for future issues of the CDSR to make it more user friendly for patients and clinicians, policy makers, health care purchasers, and the public.

Subscription: 1995 annual subscription (2 issues): £100 institutional; £75 personal

Contact:

BMJ Publishing Group
PO Box 295
London WC1H 9TE

Tel: 0171 383 6185
Fax: 0171 383 6662

CRD Database of Abstracts of Reviews of Effectiveness (DARE)

Content: Structured abstracts of good quality systematic reviews of the effectiveness of health care interventions (diagnosis, screening, prevention, treatment, health promotion, technologies, ways of organising health care, health policy). Because of resource constraints, the database currently concentrates on *Health of the Nation* topic areas (cancers, coronary heart disease and stroke, HIV/AIDS, mental health and accidents), health promotion, asthma, diabetes and topics which have been reviewed by the NHS CRD.

The structured abstracts summarise the method and content of the reviews, and comment on their rigour, highlighting points which should be taken into account when interpreting the results.

Production: Major databases (Medline, Current Contents and others) and grey literature sources have been scanned from 1994 onwards to identify relevant systematic reviews. The quality of these reviews is assessed, and structured abstracts are prepared for those which meet certain methodological criteria. All decisions and abstracts are checked by CRD researchers.

Formats: Currently available either on line (most up-to-date version) or as part of the Cochrane Library (see separate entry for *Cochrane Database of Systematic Reviews*).

Search software: Online: BRS/Search. A sophisticated searching engine. The user interface is currently being improved.

Via Cochrane Library: Windows-based software.
Relatively unsophisticated search options. No indexing as yet.

Developments: Searching options will soon be improved and made easier to use.

Subscription: Online: Free (but user must pay telephone charge)

Via Cochrane Library: see entry for *Cochrane Database of Systematic Reviews*

Contact:
NHS Centre for Reviews and Dissemination
University of York
York YO1 5DD

Tel: 01904 433634

Drug & Therapeutics Bulletin

Aims: To provide up-to-date independent evaluations of drugs and other modes of treatment.

Content: Articles which critically assess new and old drugs and treatments, examine claims made about them, comparing them with alternatives, and summarising the evidence about their benefits and disadvantages. Clear conclusions and implications for practice are given, unless the evidence is insufficient, in which case this is clearly stated. A five-year cumulative rolling index is published at the beginning of every year.

Production: Articles are based on critical assessments of published information. The producers claim to give short shrift to material which is not scientifically valid. Once a draft of an article has been prepared, opinions and comments on it are sought from about 30 consultants, and also from the manufacturers of any products mentioned. The published article reflects an informed consensus.

Notes: The Consumers' Association and the *Drug & Therapeutics Bulletin* are completely independent of pharmaceutical companies and government agencies, therefore have no commercial or official conflicts of interest. *Drug & Therapeutics Bulletin* does not hesitate to criticise pharmaceutical manufacturers or government bodies if it feels this is necessary.

Intended audience: Prescribers and pharmacists

Format: 8 pages

Frequency: Monthly (was fortnightly until 1994)

Produced by: Consumers' Association

Published by: Which? Limited

Subscription: Standard annual subscription £41

Contact:

Editorial
Drug & Therapeutics Bulletin
2, Marylebone Road
London NW1 4DF

Subscription
Dept DTB, Consumers' Association
Castlemead
Gascoyne Way
Hertford SG14 1LH

Effective Health Care bulletins

Aims:	To provide health care purchasers and providers with current, scientifically valid information about the effectiveness and acceptability of specific health care interventions, and to produce recommendations based on the interpretation of the current evidence.
Content:	A systematic review and synthesis of the literature about the clinical effectiveness, cost-effectiveness and acceptability of a particular health service intervention (each bulletin addresses one topic). The bulletins are written to be understood by people without specialist clinical training.
Production:	Relevant and timely topics for review are selected by a steering group comprising health service managers, directors of public health and academics. Topic selection criteria include: resource implications; uncertainty about effectiveness; and potential impact on health. A review team undertake literature searching, appraisal and synthesis of information according to established systematic review methodologies. Relevant experts serve as advisers to each bulletin, and each bulletin is extensively peer-reviewed.
Notes:	Funded by the Department of Health. Views expressed are those of the Effective Health Care team, not necessarily those of the DoH.
Intended audience:	Practitioners and decision makers within the NHS. Circulation of individual bulletins depends to some extent on the topics addressed.
Format:	8-12 page A4 bulletin
Frequency:	Bi-monthly
Produced by:	NHS Centre for Reviews and Dissemination (from 1995). Originally by a consortium of Nuffield Institute for Health (Leeds), Centre for Health Economics (York) and Research Unit of the Royal College of Physicians (London).
Published by:	(From 1995) Churchill Livingstone
Subscription:	For 8 bulletins: £40 for individuals, £65 for institutions
Contact:	*Production, content* NHS Centre for Reviews and Dissemination University of York York YO1 5DD *Subscription* Louise Ashworth Churchill Livingstone Maple House 149 Tottenham Court Road London W1

Effectiveness Matters

Aims: To provide an easily accessible update on the effectiveness of important health interventions for practitioners and decision makers in the NHS.

Content: A summary of the best available research evidence about the effectiveness of one particular intervention, or of several interventions which might be used in the treatment of one condition. The evidence is based on systematic reviews or large-scale, high quality randomised controlled trials which have been carried out by research teams outside of the NHS Centre for Reviews and Dissemination. The summary is written in an accessible, journalistic style and includes clear recommendations for policy and practice.

Production: A research team at the NHS Centre for Reviews and Dissemination prepares a summary of the results of major randomised controlled trials or systematic reviews which have been conducted by other research teams and which are deemed to be of importance to the NHS. The summary is extensively peer-reviewed.

Notes: *Effectiveness Matters* is sent free to key practitioners and other potential decision makers in the NHS. The distribution list may vary according to the topic addressed.

Intended audience: Practitioners and decision makers in the NHS

Format: 4 A4 sides

Frequency: 3 or 4 per year

Produced by: NHS Centre for Reviews and Dissemination

Published by: NHS Centre for Reviews and Dissemination

Subscription: Free

Contact:
Publications Office
NHS Centre for Reviews and Dissemination
University of York
York YO1 5DD

Tel: 01904 433634
Fax: 01904 433661
e-mail: revdis@york.ac.uk

Evidence Based Medicine – The Journal

Aims: To help clinicians keep abreast of clinically important and scientifically sound new knowledge.

Content: Structured abstracts summarising good quality research articles published elsewhere, together with expert commentaries to place the reports in the context of other evidence on the same topic and make clear the implications for practice. Educational material describing how to practice evidence-based medicine, and editorials of general interest.

The scope of the journal includes: general practice; internal medicine; general surgery; obstetrics and gynaecology; paediatrics; psychiatry; anaesthesiology and ophthalmology.

Production: Researchers scan over 50 primary research journals for articles of relevance to clinical practice. They assess the methodological quality of those which are relevant, and select those which are scientifically rigorous. They prepare a structured abstract of about 400 words, which is carefully checked for accuracy. Selected experts prepare a commentary which puts the article in context and draws out any key messages for clinical practice.

Notes: See related entry for the *ACP Journal Club*

Intended audience: Medical professionals

Format: Journal

Frequency: Bi-monthly

Produced by: McMaster University, Canada, and Centre for Evidence Based Medicine, University of Oxford

Published by: American College of Physicians and BMJ Publishing Group

Subscription: Volume 1 (7 issues): personal rate £50; institutional rate £80; BMA member's rate £35

Contact:

Editorial
Professor D. Sackett
Centre for Evidence Based Medicine
Level 5, Oxford-Radcliffe NHS Trust
Headington
Oxford OX3 9DU

Subscription
BMJ Publishing Group
PO Box 299
London WC1H 9TD

Tel: 0171 383 6270
Fax: 0171 383 6402

Informed Choice Leaflets

Aims:	To provide women and health professionals with clear summaries of the best available evidence about interventions during pregnancy and childbirth, to promote effective health care and informed choice.
Content:	For each topic, there is a pair of leaflets. Both are based on up-to-date evidence and are explicit about the risks, benefits and uncertainties associated with treatments. The women's version is illustrated with colour photographs and the language is kept simple (Plain English kitemark awarded). The professional version (which may be suitable for women wanting more detailed information) is fully referenced.
Production:	Subject experts draft the text for the professional version of the leaflets based on a systematic review or the best available evidence. This is peer-reviewed by international experts. The text for the women's version of the leaflet is drafted by a journalist using information from the professional version. The leaflets are tested among focus groups of health professionals and women.
Notes:	It is intended that women will be given the leaflets health professionals as an integral part of the care process. A pilot study of the use of two leaflets in practice showed that women found them readable and helpful. A major evaluation of the leaflets is planned.
Intended audience:	Users and providers of maternity services
Format:	Pairs of professionally produced illustrated leaflets
Frequency:	The first five sets of leaflets have been available since January 1996. Five more sets will be available from late 1996
Produced by:	MIDIRS (Midwives Information and Resource Service) and NHS Centre for Reviews and Dissemination
Published by:	MIDIRS
Subscription:	Contact MIDIRS
Contact:	MIDIRS 9 Elmdale Road Clifton Bristol BS8 1SL Tel: 0117 9251791

King's Fund Promoting Patient Choice projects

Aims: To develop materials to give clinical information about specific conditions with a view to helping patients participate in treatment decisions.

Content: Seven health topics will be covered, with information presented in different media.

- Incontinence: CD-interactive plus accompanying leaflet.
- Colorectal cancer: leaflets, linear video, CD-ROM multimedia treatment pathway
- Inflammatory bowel disease: linear video and leaflets
- Childhood bed-wetting: multi-media on CD-ROM
- Post-operative pain control: leaflet and audio cassette (several languages) and linear video
- Hormone replacement therapy: interactive video plus leaflet
- Anxiety and depression in Asian women: audio-cassettes and leaflets (several languages)

Production: Seven project teams have been commissioned to develop the materials. They will be endeavouring to ensure that the materials reflect the most up to date research evidence about treatment findings, and will be involving both medical staff and specific user groups in their development.

Intended audience: Relevant patient and professional groups

Produced by: Various project teams funded by the King's Fund Development Centre

Contact:
Promoting Patient Choice Project Manager
King's Fund Development Centre
11–13 Cavendish Square
London W1M 0AN

Tel: 0171 307 2669
e-mail:cnmarkd@kehf.org.uk

MeReC Bulletin

Aims: To provide unbiased information which will encourage and enable GPs to prescribe rationally, safely and cost-effectively.

Content: Summary reviews of either major new drug products, drugs within the same therapeutic category, or the treatment of common conditions seen in general practice. The bulletins address issues of effectiveness, safety, appropriateness, acceptability and costs of drug treatments, and give practical advice to general practitioners. Usually one or two topics are addressed in each issue.

Production: Literature reviews are conducted by a team of drug information pharmacists, and a range of expert opinion is sought. Articles are peer-reviewed by experts in the relevant field, clinical pharmacologists and drug information pharmacists.

Notes: Topics for the MeReC Bulletin are mainly suggested by FHSA prescribing advisors and GPs. The MeReC team maintain close links with the *Drug & Therapeutics Bulletin* and the *Prescribers' Journal* to ensure there is no unnecessary duplication of topic coverage. The Medicines Resource Centre is funded by the Department of Health and has no commercial conflicts of interest. *MeReC Bulletin* is sent to every GP in England. Scotland and Wales have their own Medicines Resource Centres (see separate entries).

Intended audience: General practitioners in England. The bulletin is also sent to community pharmacies.

Format: 4 A4 sides

Frequency: Monthly

Produced by: Medicines Resource Centre

Published by: Medicines Resource Centre

Subscription: Free to all GPs and relevant health care professionals in the NHS

Contact:
Nick Hough, Director
Medicines Resource Centre
Hamilton House
24 Pall Mall
Liverpool L3 6AL

Tel: 0151 231 6044
Fax: 0151 236 2039

SCHARR Guide to Evidence Based Practice

Aims: To help people identify useful sources and resources in support of evidence-based practice.

Content: Bibliographic references, contact details and addresses for useful Internet sites, listed under the headings of: introductory material; literature searching; managing the review process; critical appraisal; economic evaluation; scales and checklists; meta-analysis; the information worker's role; dissemination and changing practice; journals, newsletters and bulletins; on-line databases; Internet resources; discussion lists; the Cochrane Collaboration.

Production: Information staff at the Sheffield Centre for Health and Related Research have identified sources which may be useful to those concerned to promote and practise evidence-based health care.

Notes: The *SCHARR Guide* would be a useful complement to this series of readings and this source guide. *The SCHARR Guide* includes a wider range of references and source details, particularly for Internet resources, although it contains less detail and is not so focused for consumer health information providers as this series.

Intended audience: People wanting to know more about evidence-based health care

Format: Available in hard copy (see below). Will soon be available on the World Wide Web

Produced by: Sheffield Centre for Health and Related Research

Cost: £5.00 per copy

Contact: Andrew Booth
SCHARR
Regent Court
30 Regent Street
Sheffield S1 4DA

Tel: 0114 282 54543

SMRC Bulletin

Aims: Medicines Resource aims specifically to meet the drug information needs of GPs and community pharmacists, and thus to promote rational, safe and cost-effective prescribing.

Content: One or two topics are addressed in each issue. These may include summaries of new products, new applications for product licences, or issues about the treatment of common conditions. A balanced view of all aspects of drug treatment, including efficacy, side-effects, cost and cost-effectiveness are dealt with. Summaries of relevant Scottish Office reports may be included.

Production: In most cases the bulletins are written by a team of drug information pharmacists in the Scottish Medicines Resource Centre. Some bulletins are commissioned from specialists. Bulletins are checked by a broad-based editorial board and are peer-reviewed by relevant consultants.

Notes: The topics for bulletins are selected by an editorial board, with input from Health Boards. Suggestions from readers are also welcome. The bulletins are sent free of charge to all GPs and community pharmacists in Scotland. The Scottish Medicines Resource centre is an NHS department.

Intended audience: GPs and community pharmacists in Scotland

Format: 4 A4 sides

Frequency: Ten issues annually

Produced by: Scottish Medicines Resource Centre

Published by: Scottish Medicines Resource Centre

Subscription: Free

Contact:
Scottish Medicines Resource Centre
Elliott House
Hillside Crescent
Edinburgh EH5 7EA

Tel: 0131 557 3733
Fax: 0131 557 6883

The NHS Centre for Reviews and Dissemination

The NHS Centre for Reviews and Dissemination (CRD) was set up in January 1994 at the University of York. It has two main aims:

- To increase the research-based information available to the NHS, particularly on the effectiveness and cost-effectiveness of health care interventions.
- To disseminate this information effectively in a targeted way to the relevant professionals in the NHS and to consumers of its services.

The CRD undertakes and commissions systematic reviews of the effectiveness and cost-effectiveness of health care interventions. It focuses on topics which are recognised as current priorities within the NHS, for example because there is much uncertainty about a particular treatment, because there are wide variations in practice, or because an intervention is being given to many people (possibly at a high cost), but is of uncertain benefit.

Researchers at the CRD are also compiling databases of structured abstracts of good quality published systematic reviews of the effectiveness and cost-effectiveness of health care interventions and the management and organisation of health services (see separate entry). The quality of published reviews is assessed, and for those which satisfy certain methodological criteria, structured abstracts are prepared.

The CRD aims to disseminate information based on the reviews it undertakes and commissions, on reviews produced by the Cochrane Collaboration, and on other rigorous evidence, in accessible formats. In addition to detailed reports, it produces *Effective Health Care* bulletins and *Effectiveness Matters* (see separate entries).

The CRD also carries out some primary research to assess the effectiveness of different approaches to disseminating and implementing evidence-based health care.

There is an enquiry service at the CRD which is available to consumer health information providers (but not to individual consumers). Information staff will help answer specific questions about reviews on the effectiveness and cost-effectiveness of health care interventions and the delivery and organisation of health care.

The CRD and the UK Cochrane Centre are both part of the NHS R&D Programme, and work closely together. The CRD will not carry out reviews on topics which are already the subject of Cochrane reviews: it responds to needs within the NHS to produce reviews on topics which Cochrane volunteers are not already addressing.

NHS Centre for Reviews and Dissemination
University of York
York YO1 5DD
Tel: 01904 433634

The Cochrane Collaboration and the UK Cochrane Centre

The aim of the Cochrane Collaboration is to produce and maintain high quality systematic reviews of randomised controlled trials which reflect the best currently available evidence about the effectiveness of various aspects of health care.

The Cochrane Collaboration is an international network of people, including health care professionals, researchers and consumers, who prepare, maintain and disseminate systematic reviews. Collaborative review groups focus on particular health problems or clinical specialties. Within each collaborative review group, an editorial team helps to ensure that reviews are prepared to a high standard.

There are several Cochrane Centres throughout the world which co-ordinate and support the work of identifying all the relevant randomised controlled trials and preparing and disseminating systematic reviews. They promote research to improve the quality of reviews, develop policies and set standards, and co-ordinate the development of the Cochrane Collaboration. The UK Cochrane Centre is based in Oxford (address below) and directed by Iain Chalmers.

Systematic reviews produced by the Cochrane Collaboration are published electronically as in the Cochrane Database of Systematic Reviews (see separate entry).

The UK Cochrane Centre
Summertown Pavilion
Middle Way
Oxford OX2 7LG
Tel: 01865 516300

Glossary

Critical appraisal is a means of assessing the usefulness and validity of information for a particular question or decision. It is important because it is unlikely that all the research evidence on a topic will be relevant to a specific question, and not all research evidence is of the same quality.

The **effect size** of a treatment is a numerical estimate, derived from research, of how well a treatment works. Effect sizes might estimate the proportion of people treated with a particular intervention who got better by a certain amount, or the extent to which, on average, people got better (for example, how many more days longer they lived or by how much their symptom severity was reduced).

The **effectiveness** (or clinical effectiveness) of a health care intervention is the extent to which, in practice, it is likely to do more good than harm. This is sometimes contrasted with the **efficacy** of an intervention, which is the extent to which it is likely to do more good than harm in ideal conditions.

Evidence-based health care can be defined as an approach to health care which involves finding and using up-to-date research into the effectiveness of health care interventions to inform decision making. Evidence-based health care is health care which has been rigorously tested in practice and been shown to be effective.

Framing. Many messages can be couched in either positive or negative terms. Positively framed messages talk in terms of what is to be gained, such as survival and recovery. Negatively framed messages talk in terms of loss, such as mortality and relapse.

Meta-analysis is the process by which the results (numerical estimates, for example of the size of effect of a treatment) of individual studies are combined using statistical techniques to produce a single summary numerical estimate. A meta-analysis is a review which involves a quantitative synthesis of the results of individual studies.

An **outcome** of a treatment is a result or effect of that treatment. For example, if a treatment caused a person's life to be extended by a year, the extra year of life would be an outcome of that treatment. Health care interventions may have a variety of positive and negative, intended and unintended outcomes.

A **placebo** treatment is a pill, potion or procedure which would not be expected to be effective because it has no known active drug ingredients or specific healing properties.

Prognosis refers to the future course of an illness. A person who is told they have a poor prognosis is likely to get worse rather than better.

Randomised controlled trials are usually the best type of study to assess the relative effectiveness of two interventions. A basic randomised controlled trial involves assigning people randomly to two groups, the experimental group and the control (or comparison) group, to ensure that the two groups are as similar as possible at the start of the trial. The experimental group are given the (new) intervention which is being tested and the control group are given an alternative, often either a current standard treatment or a placebo. The two groups are followed up to see if there are any differences between them. This allows the effectiveness of the two interventions to be compared.

There are several ways of presenting **risk statistics**, including:

- The **absolute risk reduction** is the difference between the absolute risks associated with a particular treatment and the absolute risks of no treatment or of a different treatment. The risk of no treatment is subtracted from the risk of treatment.

- The **number needed to treat** tells you how many people have to be given a particular treatment in order for one positive outcome to be achieved which would not have occurred if they were given no treatment or a different treatment.

- The **relative risk reduction** expresses the differences in the rates of negative outcome between groups given different treatments. The difference in the rates of negative outcomes between treatment and control groups is divided by the rate of negative outcomes in the control group.

Systematic reviews provide clear and unbiased overviews of the research available to answer a specific question. They involve a comprehensive literature search, and use explicit criteria to determine which individual research studies will be included, what information will be extracted from each study, and how that information will be assessed and combined to provide a valid summary of the available research.

Utility is a concept akin to overall well-being or satisfaction. Things which people value and want to maximise are said to have utility for them. Good health has utility for many people, but so do other things. There is some debate about whether the goal of health care is to improve a person's health or to increase their overall utility.

The need to provide more information to individual patients and the wider public about health care is becoming generally accepted. *Information about Health Care Effectiveness* offers an extensive guide to the wide range of communication techniques and innovations that are involved in communicating with consumers of health care. Written for people working in consumer health information services, *Information about Health Care Effectiveness* provides a step-by step guide to understanding the theory and practice surrounding the evidence-based approach to health care. It also includes an invaluable reference guide to sources of information about health care effectiveness.

Promoting Patient Choice

The publications in the Promoting Patient Choice series are part of a continuing programme of work within the Clinical Change Programme at the King's Fund Development Centre.
For the past five years, the programme has been promoting concepts and materials which help patients and the wider public to become involved in their own treatment and health care decisions. Government initiatives such as *The Patient's Charter* and *Local Voices* have created major changes in patients' rights and responsibilities and have sought to involve the public in decision-making on a wider scale. The Promoting Patient Choice programme has supported a number of projects, including the use of interactive videos for shared clinical decision-making and a survey of consumer health information services.
Each book in the Promoting Patient Choice series tackles a specific set of issues and is intended to help change and develop professional and public attitudes towards patients' involvement in health care.

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