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Improving your healthcare
Knowledge is not power. Getting the right information and learning how to apply it to your life is power.

Powter

When you’re looking for information to help guide your health decisions, there are a few important criteria to consider. Your decision should be based on the best available research evidence, and it is more likely to be meaningful if it can be personalised in some way so that it helps you to consider what’s important to you.

This was the conclusion of a systematic review of randomised trials about effective ways to communicate with patients. The review found that there are many useful formats. But no matter what format the information comes in – whether verbally or in a magazine article or from an interactive website – you should remember these criteria. And, ideally, the information should be able to answer all five of our ‘smart health choice’ essential questions.

Read on and you will discover some practical tips for finding and assessing the best evidence, whether from a practitioner, the Cochrane Library, the internet, organisations, universities, libraries or companies.
Evidence from your practitioner

Verbal

It is often enough to have your practitioner discuss with you what the evidence-based guidelines recommend, or tell you about recent systematic reviews or randomised controlled trials. Whether this will be sufficient will depend on the seriousness of your condition and your relationship with the practitioner. Don’t forget to ask about the evidence, even if it is not offered. Asking the question ‘What’s the evidence?’ is more likely to obtain a detailed response than simply asking ‘Is there good evidence to support this?’ Some cancer specialists are realising that it is sometimes difficult to absorb everything that is being discussed and they offer to record the consultation so that cancer patients can go over things and think about them at home.

Written leaflets, booklets

It is often useful to have some written information to take away to consider and discuss with others. It may be some information prepared for patients and consumers, or evidence-based guidelines or even systematic reviews or randomised controlled trials.

However, not all written information is evidence based or of good quality. An audit of breast screening invitation letters across seven countries showed that they tended to over-emphasise the benefits of mammography and under-emphasise potential risks. In most cases, women were not given detailed information about the likely impact of mammography screening.

A very useful checklist has been developed called the DISCERN instrument. It can be downloaded free or used online at www.discern.org.uk and is designed to help assess the quality of consumer health information. If you really want to check out the reliability of a source when trying to answer the ‘smart health choice essential’ questions, then the DISCERN instrument is excellent. The main quality criteria are as shown in the box.
**DISCERN**

Section 1: Is the publication reliable?

1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what other sources of information were used to compile the publication?
5. Is it clear when the information used or reported in the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?

Section 2: How good is the quality of information on treatment choices?

9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment were used?
13. Does it describe how the treatment choices affect overall quality of life?
14. Is it clear that there may be more than one possible treatment choice?
15. Does it provide support for shared decision-making?

Section 3: Overall rating of the publication

16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices
Increasingly, this is the way practitioners will be accessing information for you. Keeping written materials up to date is becoming impossible in this rapidly changing world.

Rather than digging out a photocopied leaflet from the bottom of the filing cabinet when you present with a whiplash injury, practitioners will be more likely to download the most recent consumer version of evidence-based guidelines and print you a copy to take home, complete with instructions on neck exercises and evidence-based advice on what to do and what not to do. These resources are often available in several languages. Another good example is *Cervical Screening: the facts*, available in 19 languages at http://www.cancerscreening.nhs.uk/index.html

Practitioners may also search the medical literature for you if there is time during the consultation. You can even follow up on these sources at home. As we have mentioned already, the Cochrane Library is available free in a number of countries and Medline, which is run by the US National Library of Medicine, is available all over the world via PubMed. A more comprehensive list of resources is available in Chapter 15.

Instead of thumbing through a vaccine handbook when asked what vaccines you will need for an upcoming backpacking trip to south-east Asia, practitioners may look up the Centers for Disease Control and Prevention website at www.cdc.gov/travel. This website is updated daily and gives advice about the latest outbreaks around the world including bird flu and, before that, SARS (severe acute respiratory syndrome). You can type in what countries and regions you will be visiting and get advice on immunisations and antimalarials, plus other valuable information about water quality and other travel hazards.

Below is an example of how you might obtain evidence from a practitioner. In brackets we show how the conversation relates to the five questions raised in Chapter 5.

Robert is travelling back from a trip to the USA, browsing through a magazine he had bought there. He notices an advertisement for a particular antibiotic to treat childhood ear infections,
which describes what antibiotics are and how they work, but does not provide any information on whether they do actually work. Robert ponders on this. A while back, his 3-year-old son, Jeremy, had a rash that was thought to be a side effect of a course of antibiotics. This has made Robert well aware that any potential benefit may be bought at some harm.

A few weeks later, Jeremy develops a fever and complains of a sore ear, and Robert takes him to his doctor, Frank, who diagnoses a middle-ear infection.

**Frank:** ‘A course of antibiotics should do the trick. Keeping in mind that he reacted adversely to the last lot, I’ll prescribe a different one this time.’

**Robert:** ‘I was wondering, Frank, are antibiotics really necessary? I’m loath to give him yet another course unless it’s absolutely necessary. What will happen if we wait for a while to see if it gets better?’ [Q1: What will happen if I wait and watch?]

**Frank:** ‘Ear infections are likely to be bacterial, and I always prescribe antibiotics in these situations.’

**Robert:** ‘I see. So are antibiotics the only option then?’ [Q2: What are my options?]

**Frank:** ‘Well another option is to treat with paracetamol to relieve the fever and pain, but it won’t have any effect on the infection itself or possible complications from the infection. Remember, Robert, even though antibiotics have risks, they’re very low.’

**Robert:** ‘Mmmm. I suppose what I’m after is some idea of how effective antibiotics really are for ear infections. You say the risk is low, but it may not be worth taking if there’s no proven benefit. And I know paracetamol is pretty safe.’ [Q3: What are the benefits and harms of the options?] ‘Is there an evidence-based guideline? Or a randomised controlled trial?’

**Frank:** ‘As a matter of fact, I’ve used the Cochrane Library a number of times. Let’s see what it says about ear infections.’
Turning to the computer on his desk, Frank searches for the relevant abstract and finds a systematic review of several randomised controlled trials. To his surprise, antibiotics do not seem to have any effect in reducing pain during the first day of the infection. After an average of 4 days, 80 per cent of patients settle without treatment. However, for those 20 per cent of children who still have pain after that time, antibiotics do seem to help.

Frank: ‘Well, there you are then. From this it would seem there’s no harm in waiting for 24 hours to see how Jeremy settles just with paracetamol – if that’s what you want to do. I’ll give you a prescription for antibiotics just in case you need it after that.’

Robert: ‘Sounds perfect, thank you. I’ll let you know how he does. By the way, I found that very helpful. I have all the information I need for now. Thanks again.’

This is a very satisfactory outcome for Robert and Jeremy, and for Frank too.

Evidence from companies providing products and services

Companies – whether they are making pharmaceuticals, vitamins or diagnostic tests – generally have one major aim: to make profits, whether for their shareholders or private owners. It is important to keep this in mind when evaluating claims made by those with a commercial interest at stake – especially if they are superlative claims substantiated by poor evidence based on inconclusive studies or theoretical explanations of how the product SHOULD work!

Many drug companies have websites with substantial information about their products. You will recall the warnings earlier in this book about being aware of some of the pitfalls of taking evidence at face value where there are commercial interests at stake.
Ask to see the evidence for their claims. And evaluate it using the same criteria that you would use for assessing any research (see validity guides in Chapter 9). Using these criteria will help you determine if the research has been designed to push a particular interest.

**Evidence from organisations**

Many organisations provide health information. You may find yourself looking up information and it can be difficult to tell what’s reliable and what’s not. Try to answer the five ‘smart health choice’ questions and keep in mind the DISCERN criteria when you are trying to assess how reliable a source is. Websites for the following categories are listed in the section on Useful contacts later in the book.

**Evidence from the Cochrane Library**

As discussed in Chapter 10, the Cochrane Library provides what is almost certainly the most powerful, growing, single source of
evidence about the effects of healthcare. It provides regularly updated, electronically accessible systematic reviews on thousands of treatments. Recently the Cochrane Collaboration decided to withdraw any systematic review that had not been updated within the last 5 years. So you should be fairly confident that the information there is up to date. Another new initiative is that many of the systematic reviews now have lay summaries in plain English, which should make the evidence much more accessible to everyone, not just high-powered researchers!

**Consumer health bodies and self-help groups**

There are many groups that have been largely set up by consumers to support each other and offer information, advice and advocacy for others suffering with the same condition. One example in the UK is Breast Cancer Care (www.breastcancer.org.uk) and in Australia the National Breast Cancer Network of Australia (www.bcna.org.au) whose website contains a range of patient stories, brochures, booklets and links to other organisations. Newsletters and support groups are also linked. A more comprehensive list is included at the back of this book.

**General government health departments and other official organisations**

These can provide information about health policies and contact details for other organisations. Some may be able to provide information about hospitals and other health services, such as whether they are accredited or have services for patient support or complaints. They may also be able to investigate if you have had problems with a health service or product. In the UK the NHS National Library for Health at http://www.library.nhs.uk/ provides evidence-based guidelines and consumer information. In Australia, the National Health and Medical Research Council (NHMRC) produces a variety of information booklets and guidelines aimed at consumers and health professionals (www.nhmrc.gov.au/publications). State governments also provide consumer health information on their websites.
Cancer councils and specialist associations

Cancer councils are generally community-based organisations committed to preventing cancer and enhancing the quality of life for people with cancer and their families. They provide information, education and support, and also fund research and professional development. For the UK go to Cancer Research UK (www.cancerresearchuk.gov) and in Australia links to the Cancer Council in each state can be found at Cancer Council Australia (www.cancer.org.au/Home.html). Specialist associations exist for many diseases, disorders and other conditions. To find a specialist service or a medical specialist appropriate to your needs in your area, in the UK look via NHS Direct (www.nhsdirect.nhs.uk/). In Australia the Australian Medical Directory, apart from listing the details of all registered medical practitioners, includes a section on professional and specialist medical groups.

Complementary medicine or alternative health associations

There are many complementary medical associations, representing both medically qualified and non-medical practitioners. Although there is some good quality research in this area, on the whole there are fewer high-quality studies investigating complementary than orthodox therapies. The same evaluation criteria should be applied to all doctrines of healthcare. Examples of good studies on complementary medicine are available on the Cochrane Collaboration website and are published in major medical journals.

University research groups

Some research groups make their evidence-based tools available for consumers on their own websites. Decision aids, such as the ones we saw earlier for preventing strokes in patients with atrial fibrillation, can be found on the Ottawa Health Research Institute website (decisionaid.ohri.ca/decaids.html) and the Sydney Health Decision Group website (www.health.usyd.edu.au/shdg). The German
Institute for Quality and Efficiency in Healthcare has been publishing consumer-friendly versions of Cochrane reviews at Informed Health Online, www.informedhealthonline.com. Harvard University also has a disease risk assessment tool at www.yourdiseaserisk.harvard.edu, and the list goes on.

**Local hospitals and family practices**

Some local hospitals may have information resources or ideas on where to get the information that you need. Increasingly, the larger hospitals in many countries will provide substantial patient information on their websites. For example, Great Ormond Street Hospital for Children in London (UK) and the Royal Children’s Hospital in Melbourne (Australia) have comprehensive sections for parents and children (www.ich.ucl.ac.uk and www.rch.org.au). Increasingly, many general practices are putting up websites with information about their doctors and practice facilities. Some are also adding recommended health information websites.

**Surfing the internet yourself**

Doing research on the Web is like using a library assembled piece-meal by pack rats and vandalized nightly.

*Roger Ebert*

Information is the currency of democracy.

*Thomas Jefferson*

Media manipulation in the U.S. today is more efficient than it was in Nazi Germany, because here we have the pretense that we are getting all the information we want. That misconception prevents people from even looking for the truth.

*Mark Crispin Miller*

The twenty-first century is a time in history like no other when one considers the amount of information available to the average person each day through radio, TV and the internet. An estimated 13.9 million households (57 per cent) in the UK had home internet access
in April 2006, with similar figures for other developed countries such as Australia, Canada and the USA. Each year, this proportion increases and over half of these households now have broadband connections, enabling linkage to larger quantities of information at higher speed.

Just from the brief list of organisations and sources that we have shown above, you might already be starting to feel overwhelmed. The problem of information overload is only going to get worse as more and more people publish information on the web.

But be aware that much is unreliable; it can take quite a bit of time and effort to determine what is valid and relevant to your needs. It would probably be unwise to make major decisions about your healthcare solely on the basis of information obtained through the internet, without first discussing it with your practitioner and checking the quality of its source as described earlier in this book.

One way of increasing the chance of getting valid guidelines or other high-quality research is to restrict your searches to university or government agencies. You can do this in some search engines. For example, Google Scholar (www.scholar.google.com) searches academic publications, professional organisations, universities and peer-reviewed papers.

This problem of information overload has been recognised and many governments are establishing consumer information portals. The UK has the National Electronic Library for Health www.library.nhs.uk/Default.aspx and the Australian Government’s one is called Health Insite www.healthinsite.gov.au. You can be fairly confident in the reliability of information on these sites because they have been checked by an expert in advance. You still need to be alert, however, because bad information can still slip through the net.

**How people use the internet in healthcare decision-making**

The internet is a common source of health information for consumers. Surveys of internet use have consistently shown that more than half of internet users access health information. US reports claim that 62 per cent of internet users, or 73 million people,
in the USA have gone online at some point in search of health information and about 6 million people go online for advice in a typical day.\textsuperscript{6,7} Most commonly people were looking for disease information, material about weight loss and facts about prescription drugs. Typical health advice seekers went online only occasionally to look up something specific and most of them did so without getting \textit{any} advice from family, practitioners or others on \textit{where} to look for reliable information. Despite this lack of guidance, most people said that they found useful websites and that it had helped them in their health-care decision-making.

People varied a lot in whether they would systematically check that a site could be trusted. Only a quarter said that they always looked for quality criteria such as the source of the information and when it was posted. But most people (73 per cent) said that at some point they had decided not to rely on a particular website. Most commonly they had rejected it because it appeared to be overly commercial, they couldn’t work out how up to date it was, it had an unprofessional design or they couldn’t find the source of the information.

There’s no doubt that with so many home computers now linked to the internet ‘surfing the net’ is a very convenient way for patients to look things up. No longer do you have to go to your local library or bookstore in search of the information that you want. The internet is not just convenient, it’s also flexible. People generally don’t know in advance how much health information they will need. At different points in time they will want different information on different topics and on the same topics at different levels of detail. The internet can accommodate this constantly changing requirement for information.

One UK study of cancer patients and their families found that people used the internet in many different ways. Some of the questions for which they sought answers were very similar to the five questions from the ‘smart health choice essentials’. They fit under seven broad categories suggested by Ziebland and quoted here below:\textsuperscript{8}

1. \textit{Before visiting the doctor}: to discover the possible meaning of symptoms.
2. *During investigations:* to seek reassurance that the doctor is doing the right tests; to prepare for the results; and to improve the value of the consultation.

3. *After the diagnosis:* to gather information about the cancer (including information that is ‘difficult’ to ask about directly); to seek advice about how to tell children; to contact online support groups; to seek second opinions; to make sense of the stages of disease; to interpret what health professionals have said; and to tackle isolation.

4. *When choosing treatments:* to find information about treatment options and side effects, experimental treatments, research, and alternative and complementary treatments.

5. *Before treatment:* to find out what to take to hospital, what will happen, what it will be like, what to expect of recovery, how to identify and prepare questions to ask the doctors.

6. *Short-term follow-up:* to find information about side effects, reassurance about symptoms, advice about diet, complementary treatments, benefits and finances; to check that the treatment was optimal and what the perceived therapeutic benefits are.

7. *Long-term follow-up:* to share experience and advice, contact support groups and chat rooms, campaign about the condition, make anonymous enquiries.

**The relationship between the internet and the health practitioner**

Clearly, there’s no getting past the convenience and flexibility of the internet for people to access health information and this is likely to become even more commonplace. There’s no delay or wait for an appointment to start seeking answers to health-related questions. And people are using ‘the net’ for this and other aspects of their lives. In a similar way, we no longer need to pay our bills in person or even by post; we can do our banking online and even book our holidays without going anywhere near a travel agent.

What, then, is the role of the health practitioner in this age of ‘armchair information’? Despite accessing web-based information from home, most people *still* prefer to get definitive advice from
their health practitioner. But they would like to supplement it with other resources and would appreciate their doctor pointing them towards reliable internet resources. The consultation of the future is likely to take on a very different shape as a result of this. Practitioners will increasingly suggest to patients that they refer to particular resources and consider their options before returning to discuss further. This gives people time to reflect on good quality information and discuss it with their family and friends if desired. As practitioners increasingly practise evidence-based healthcare the involvement of patients in the decision-making process becomes much more of a partnership, and guiding patients towards good quality information sources is an important part of their role.

Looking for good quality health information on the internet

The UK Department of Health has stressed the importance of access to good quality information in the White Paper Better Information, Better Choices, Better Health – Putting information at the centre of health (December 2004).

Over the past decade several tools have been developed to try to rate the quality of health information on websites, but most of them have not been very useful and have been discontinued. Recently, the British Medical Association (BMA) has suggested that there are six broad issues that should be considered when looking at a health information website. A similar list has been developed by the Australian Government’s Health Insite and the US National Institutes for Health.

**BMA quality criteria for health websites (www.bma.org.uk)**

1. Is the site regularly updated? Information on the review process – for example, the most recent review date – should be given on the site.
2. Does the site give references and sources for the information it provides?
3. Does the site provide information about who compiled the site (the organisation or individual)?
4. Does the organisation give an address/other contact details?
5. Spelling and grammatical mistakes – more than a couple of these indicate a weak site that has not been properly edited or reviewed.
6. Is the organisation trying to sell something? If so, be wary of the information.

Government websites for reliable health information

A number of government initiatives have been set up to provide consumers with good quality health information. In the UK, the National Library for Health has several patient resources that are reliable and useful: www.library.nhs.uk/forpatients

1. NHS Direct has been established to provide 24-hour e-health and telephone support to consumers to enable them to make decisions about their healthcare and that of their families. It includes a health encyclopaedia, answers to common health questions, self-help guides, a health magazine, enquiry facilities and information about finding a health service.
2. Best Treatments (produced by BMJ Publishers and free to UK residents), contains plain language summaries of randomised controlled trials and systematic reviews of treatments.
3. DiPEx is a database of patient experiences that we discuss further in Chapter 13.
4. Patient.co.uk contains free health information for common general practice problems.

The US National Library of Medicine has an extensive database of good quality information about over 700 diseases and conditions. Medline Plus (http://medlineplus.gov) also includes help with searching the internet for health information and lists of hospitals and physicians in the USA. It has extensive information about prescription and non-prescription drugs, health information from the media and also links to clinical trials.
The Australian Government has established Health Insite (www.healthinsite.gov.au) a consumer health information website that includes only content that meets certain assessment criteria and standards.

**Media reports**

The media are an ever-present and powerful source of health information for us in today’s world. In earlier chapters we highlighted the fact that many media stories rely heavily on the power of the anecdote and the telling of one person’s story. These stories can often be very helpful in providing insight into the experience of particular illnesses. As with any information source, there are good and bad examples. There are well-researched and carefully prepared reports, and there are the sensational and often misleading headlines in the tabloid newspapers.

Some evidence-based practitioners have been sharing their expertise with journalists via training workshops in recent years to help improve the accuracy of reporting on health news items. As well, several initiatives have been set up to give the media and its audiences some feedback about the accuracy of media reports and the reliability of the research they are covering. These include Media Doctor Australia (www.mediadoctor.org.au/) and Media Doctor Canada (http://www.mediadoctor.ca), while Health News Review performs a similar function in the United States (http://www.healthnewsreview.org). In the UK, the Hitting the Headlines service (http://www.york.ac.uk/inst/crd/hth.htm) provides a rapid analysis of media reports about research. Looking at the stories featured on these web services makes it clear that there is great variability in the quality of media reporting. You certainly shouldn’t be relying purely on what the headlines say when making important health decisions.

**Making sense of health stories in the media**

Medical breakthroughs make great headlines. Each week, news outlets report on research published in journals or promoted by researchers, companies or other agencies. However, these headlines
should not be taken at face value. The consistent message of this book is that you should always question the level of evidence that lies behind the catchy headlines.

Here’s a good example. In October 2006, the *American Journal of Medicine* published a study that reported an association between regular fruit juice consumption and a reduced chance of developing Alzheimer’s disease. Headlines read ‘Drinking juice may slash Alzheimer’s risk’, ‘Drinking juice might stall Alzheimer’s’ and ‘Juices may cut Alzheimer’s risk’, claiming that the study had produced ‘powerful results’ that ‘the risk was 76 per cent lower for those who drank juice more than three times a week compared with those who drank it less than once a week’.

However, what is not explained by the media is that this study was a cohort design and, as discussed earlier in this book, such a design is prone to bias. It may be that people who drink juice more than three times per week are in better health generally, exercise more, and have higher education levels and better diets. What we would really need to do to answer this question is randomise people to high and lower fruit juice consumption for a period of perhaps 10 years (as this was the timeframe for the other study). It may be that we find through this process that increased fruit juice consumption actually has the opposite effect and increases the chance of Alzheimer’s disease.

Apart from study design it is important to look at the actual (or absolute) numbers of people affected by a treatment or behaviour change. When the original article is considered, there is a very strange pattern in the results. The number of people probably free of Alzheimer’s disease is greater in people who drink *juice less than weekly* (compared with once or twice a week). The number free of Alzheimer’s disease drops to 16 per 100 with one to two juices per week and then increases to 49 per 100 with three or more juices per week. It is very difficult to explain why the Alzheimer’s disease risk doesn’t consistently fall with greater juice consumption. This is called a dose–response relationship and is another thing to consider when looking for a cause-and-effect relationship.

A similar example comes from a media report that ‘decaffeinated coffee may cause heart problems’. When you look more
closely at this story, the study was not a randomised trial and was prone to bias. You may want to change from drinking decaffeinated coffee to the standard variety, but it should not be done on the basis of changing your heart disease risk.

As we are bombarded with new health headlines in the media each day, it can be difficult to know how to make sense of them all. There are two common pitfalls in media reporting of research. One is that they overstate the validity of results from studies that are not randomised controlled trials and therefore prone to bias. Second, they often report effects in relative terms rather than absolute. A 20 per cent reduction in something that is very common will have a greater impact than a 20 per cent reduction in a rare event. For example, if a disease is fairly common (for example, the common cold) you might estimate that 80 out of 100 people in the community will get one over winter. A treatment that reduces your chance of getting the common cold by 20 per cent will mean that only 64 people out of 100 will get ‘a cold’ if they all take the treatment. On the other hand, if the treatment is less common (for example, for heart attacks) we might estimate that 5 out of 100 people might have a heart attack over the next 10 years. If a treatment reduces the chance of having a heart attack by 20 per cent then only 4 people out of 100 will have one.

For heavy duty research

University and other libraries and Medline, an electronic database of the medical literature, provide useful sources if you want to explore a health issue in great depth. Medline, which is now available free on the web, provides a database of the titles and abstracts of articles in the most important medical journals. Once you have located a study that looks relevant, you can follow it up from the reference provided. Articles are indexed by the subject that they cover – such as ‘breast neoplasms’ – as well as methodological headings – such as ‘randomised controlled trial’.

You don’t necessarily need to be a student or staff member to gain access to a university library. In many countries they are
available for use by the general public, and it may be worth checking out your local institutions’ policies. They can be useful for providing access to electronic databases, such as Medline, or to hard copy journals.

When searching journals, remember that the most reliable ones are those that are subject to quality control by peer review. This means that, before an article is published, it is submitted to other experts in the area of interest for their comments. To establish whether a journal is peer reviewed look in the ‘instructions to authors’ section where the peer review process is usually described. Examples of some such high quality journals include, *The Lancet*, *New England Journal of Medicine*, *British Medical Journal*, *Journal of the American Medical Association* and *Annals of Internal Medicine*. Many of these are also available on the internet.

Other libraries that can be useful are: local libraries, which can have links to other, larger libraries; state libraries; and libraries of specialist associations.

**Summary**

Evidence can be obtained from a variety of sources.

- **From your practitioner:** ask your practitioner about evidence-based guidelines, recent systematic reviews or randomised controlled trials. You may also want to take written copies of these home. You or your practitioner may also have access to electronically accessible databases that should provide these sources of evidence. Health practitioners can be a helpful source to guide patients towards reliable information.
- **From companies providing products and services:** the aim of companies is usually to make profits. Keep this in mind, especially if the claims are based on poor
or inconclusive studies or theoretical explanations. Companies making claims should be able to provide the evidence to support them.

- **From other organisations:** consumer-friendly information can also be obtained from health departments, cancer councils and other associations dealing with particular diseases.

- **From the internet:** although plentiful, much information from the internet is unreliable. It would be wise to discuss any information with your practitioner and appraise its quality. Certain factors should be considered (at a minimum) when finding reliable internet information:
  - who compiled the site and are they likely to have any conflict of interest?
  - how up to date is the site?
  - what is the source of its information?
  - government-funded consumer websites tend to have explicit quality assurance processes and are likely to be quite reliable.

- **From the media:** be cautious about media stories and headlines that make bold or sensational claims. Remember to ask yourself about the likelihood of benefits and harms from a test or treatment. Media headlines about health discoveries should be tested by looking into the study design and consider whether effects are reported in absolute (actual) numbers.

- **For heavy duty research:** university and other libraries and Medline, an electronic database of the medical literature, provide useful sources if you want to explore a health issue in great depth.


Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever has.

*Margaret Mead*

Many consumers now expect, quite rightly, to be involved in making decisions about their healthcare. Sharing the power also means sharing the responsibility. As consumers, we also have an important role to play in improving the quality of healthcare – we cannot leave it all to the health professionals. You can do your bit to improve the quality of healthcare and health information. One important step, as suggested in this book, is to encourage an evidence-based approach to your healthcare. Here are some other suggestions.

**Lobbying for more responsible information**

If you are confused or dissatisfied with the quality of information, whether on a prescription medicine or in a leaflet handed out by your naturopath or pharmacist, it is your right to take the matter further. Contact the source of the information and ask what evidence is available to support the claims being made. By doing this, you may end up with some useful information, as well as sending the message to organisations that the public will hold them accountable.
DOING YOUR BIT

If you are not satisfied with the response, you may wish to contact professional or industry associations, regulatory authorities or watchdog groups, such as Consumer Direct (www.consumer-direct.gov.uk/), ‘Which’ (www.which.co.uk/), the National Consumers’ Council (www.ncc.org.uk/) or EQUIP – How to complain about an NHS health service (http://www.equip.nhs.uk/support.html) in the UK, or the Australian Consumers’ Association (www.choice.com.au) or the Consumers’ Health Forum (www.chf.org.au) in Australia. Another useful group of health professionals is Healthy Skepticism (www.healthyskepticism.org), an international watchdog on the pharmaceutical industry. It has documented many instances of unethical or misleading advertising and promotion, and has been successful in having many such breaches rectified. Most countries also have government authorities that monitor or regulate such promotion: in the UK, the Trading Standards Authority (find out more at www.direct.gov.uk/en/RightsAndResponsibilities/DG_10015892) and in Australia, the Therapeutic Goods Administration (www.tga.gov.au) regulates drugs and devices.

Being part of a trial

The aim of science is not to open the door to everlasting wisdom, but to set a limit on everlasting error.

Albert Brecht, Galileo

If there are several treatments and it is unclear which is best, you may wish to consider being part of a trial. Your practitioner may suggest this to you; otherwise you may wish to ask your practitioner whether there are randomised controlled trials that you can enter.

Before a trial is started, the new treatments are tested in a laboratory to ensure, as far as is possible, their safety and effectiveness. They might also have been trialled previously on other people for preliminary information on safety. Throughout the trial details will be collected about your progress and you will be monitored for any adverse effects and, if it is found that a treatment is not in your best interest, you will be removed from the trial and your options discussed. You will receive your care in the same places that standard treatments are given – hospitals, clinics or doctors’ offices.
If you decide to participate in a trial, check whether it has been approved by an ethics committee. Ethics committees are run by hospitals and universities and include a range of scientists and community representatives. Among other things, an ethics committee makes sure that, if you enter a trial, you will not have to stop any treatment that is shown to be doing you good. Ethics approval also means that the committee thinks that the benefit-to-harm ratio of the new treatment is no better than existing alternatives. In fact, there is evidence that 50 per cent of trials show the new treatment to be better and 50 per cent show that the old treatment is better. This suggests that, on average, you will have as a good a chance of the best outcome, no matter which arm of the trial you are in. Safety guards are built into trials to ensure that they are stopped as soon as one of the treatments is shown to be better than the other.

What else is in it for you? Joining a trial may offer you the only way of gaining access to a new drug that is not yet generally available. As well, research has shown that practitioners who enter patients in trials generally offer a better standard of care. And, of course, you will be helping to further the march of knowledge as well as improving the prospects for people in the future.

**Figure 13.1** When to participate in a randomised trial

![Decision Tree](diagram)
DOING YOUR BIT

It is important to make sure that you understand what the trial entails so that you can give true informed consent to being involved. If it is a trial being run by a pharmaceutical company or other commercial interest, you should ask for an assurance that the results of the trial will be made publicly available and not kept private by the company. Trial results should be made public irrespective of the results; if you are part of a trial that shows a new treatment does not work, you want that to be made known just as much as if the new treatment does work. You may also want to request that a copy of the study results be sent to you as soon as they are available.

The decision to enter a trial depends on the magnitude of the benefits and harms and the quality of evidence as shown in Figure 13.1. Even if the evidence of benefit is not of high quality, you may still choose to use the intervention because it is thought to be free of harms. However, when it is unclear whether the benefits exceed the harms because the evidence is poor, it seems reasonable to be entered into a trial.

**Legal issues**

It seems right that people should be compensated for serious outcomes stemming from negligence. Therefore, it is important that medicine is challenged and that health practitioners are held accountable. However, we need to remember that serious outcomes may occur even when the appropriate care is given – not all diseases can be cured and nature is uncertain.

There is a growing concern that unrealistic expectations for detecting, diagnosing and treating disease often drive people to sue the practitioner or laboratory for a tragic outcome that may have arisen as an untoward effect of a reasonable process of care. Medicine is not perfect; outcomes are uncertain.

The following is an extract from Professor Fiona Stanley, an eminent Australian epidemiologist:

Recent litigation has involved women who have claimed that their [cervical] cancers were not picked up by the screening process. These situations are tragic but it is not a failure of the screening
program and it is not negligence on the part of the laboratory – it is expected as part of normal screening activity. These women were the unfortunate few, the very rare cases, the false negatives which occur in any screening program.

The effects of this litigation have been negative in the following ways. Firstly, a marked increase in referrals for slightly abnormal smears. Secondly, major increases to the costs of the program – more repeat tests, more doctors’ examinations, more colposcopies, more biopsies and so on. Thirdly, fewer women coming for screening, having been put off the program because of the adverse publicity which is usually damaging to the service and the professions whether they are found eventually liable or not. Fourthly, trained people leaving gynaecology or pathology as they do not like being sued. And lastly, encouragement to search for new technologies or tests which may bring very small gains in terms of increased accuracy but with increases in costs.

It’s not beyond the realms of possibility that the increased costs of cervical cancer screening programs could result in them being abandoned. If this community wishes to allow women and their lawyers to sue and be awarded huge damages, then we’ll have to accept that there will be more women dying of the disease.

Many doctors feel that they are being encouraged to practise defensive medicine – which means that consumers are more likely to undergo unnecessary tests and treatments – because of growing concern about the threat of legal action.

Such concerns could be allayed if more practitioners and patients used some of the processes in this book to make the best possible decisions jointly. This should improve the quality of care and reduce the number of legal suits against practitioners by making clear what expectations are realistic and encouraging optimal practice, as well as discouraging defensive medicine.
Summary

Everyone has an important part to play in improving the quality of healthcare and health information. One way is to make evidence-based decisions about your healthcare. In addition we can all do the following:

- Lobby for more responsible information by contacting the source of any health information and asking about the available evidence supporting the health claims.
- Offer to be part of a trial when there is uncertainty about which intervention is best. The advantages are:
  - it may be the only way of gaining access to a new drug that is not yet generally available
  - practitioners who enter patients in trials generally offer a better standard of care
  - you will be helping to further the march of knowledge.
- Be better informed about legal issues. Although it seems fair that people should be compensated for serious health effects resulting from negligence, many practitioners are recommending unnecessary tests and treatments because of growing concern about the threat of legal action.

References

And finally, here is our summary of how to improve the quality of your healthcare, and sift the good health advice from the masses of bad information that is out there.

**Think critically**

- **Think probabilistically**: to assess the harms and benefits of health decisions intelligently, you need to know how probable they are, as well as the source and the strength of the probabilistic evidence.
- **Beware anecdotes**: they might sound convincing but are an unreliable source of evidence. For most tests and treatments, you cannot infer a general rule from a single experience – especially if it is not your own.
- **Ask for evidence about outcomes that matter to people**: it’s not enough to know that this treatment is effective in rats or at boosting levels of chemical XYZ. Will it improve your quality or quantity of life?
- **It is your right to be informed**: don’t be intimidated by the busy schedule or manner of a practitioner. If it is not offered, ask for information that will enable you and your practitioner to choose the best available option. If advertisements, information
leaflets or media reports are unclear or do not provide enough information about the evidence on which they are based, follow them up and request the data.

*Be sceptical*: advice from those with a vested interest may be biased. Researchers have been known to push a particular aspect of their results. Always assess the quality of the evidence and, if necessary, look elsewhere for more.

*Newer is not necessarily better*: if a new health product or procedure has not been shown convincingly to be more effective or safer than one that has been around for a while, why use it?

*Many health problems get better on their own*: this is known as spontaneous remission. After an illness, we may be tempted to believe that a return to good health is the result of a treatment. Of course this may be so, but in many cases it is uncertain whether recovery is the result of an intervention or the body’s natural healing process. Because of this, we should be careful not to assume that the therapy caused the cure.

*Believing is sometimes seeing (the placebo effect)*: when people tell you that such and such a therapy made them feel better or worse, it may not be a result of the chemical or physical effect of the treatment. If we believe that something is helping us, this can affect our recovery. It’s common to experience an expected effect after treatment even if the treatment is a placebo or inactive.

**Ask key questions**

Perhaps our single most important message is the importance of asking the right questions when making decisions about your health. If you have a health problem, the five key questions to ask are:

1. What will happen if I wait and watch?
2. What are my test or treatment options?
3. What are the benefits and harms of these options?
4. How do the benefits and harms weigh up for me?
5. Do I have enough information to make a choice?
Think about all the benefits and harms

Healthcare is being revolutionised by a new movement called evidence-based medicine or evidence-based healthcare. This is encouraging the use of health practices that are based on sound evidence of their benefit exceeding their harm, rather than the opinions of experts or tradition, as has often been the case in the past and often to the detriment of our health. This book aims to help consumers play a part in this revolution and to benefit from it for themselves by learning how to distinguish the good evidence from the bad.

Health evidence can be theoretical (a theory about how or why a treatment ought to work), anecdotal (a report based on one or more individual experiences) or probabilistic (provided by information from many events, allowing predictions of how often something is likely to occur). In health research, the most compelling information comes from probabilistic evidence from studies based on groups of people. Unfortunately, however, not all such studies are of good quality and capable of providing reliable information. The randomised controlled trial (RCT) is the best study design for investigating health interventions, whether it is the effect of a new drug

Sources of evidence on the effects of interventions from strong to weak

1. An evidence-based guideline: not all guidelines are based on valid evidence so it is important to check this
2. Randomised controlled trials
3. Non-randomised studies:
   – cohort studies and non-randomised trials
   – population-based case–control studies
   – hospital-based case–control studies
   – other study types
4. Case reports, opinions, clinical impression and opinions of experts
or how a new surgical technique compares with an old. Systematic reviews of RCTs combine the results of RCTs to provide the best form of evidence available. Clinical practice guidelines, if evidence based, can provide useful information for consumers and health professionals, but it is important to check the strength of evidence to support particular recommendations.

So if you want more evidence about an option that a practitioner has advised, you should ask (in order of priority):

- **Is there a guideline?** If there is, ask if it is evidence-based. If it is, you and your practitioner should then discuss how to apply the evidence to you. If there is no evidence-based guideline for your problem, the next question is:
- **Is there a systematic review of randomised controlled trials?** If the answer is yes, again you and your practitioner should talk about how best to apply the evidence to your particular problem. If there is no systematic review, you want to know:
- **Are there randomised controlled trials?** If there are, you and your practitioner should discuss how best to use the findings to suit you. If there are no randomised trials, ask:
- **Are there any other studies?** If there are other studies, which fulfil the criteria for good cohort or case–control studies described in Chapter 9, discuss with your practitioner how they apply to you, remembering that the results of these studies are less certain than for RCTs.
- **What are the experts’ opinions or are there any case reports?** This last question is on pretty shaky ground due to the lack of evidence being considered. It is really the last resort if the answer to all of the previous questions is definitely NO. If your only option is to rely on this, the general advice would be to use the recommendation if it seems safe, but avoid it if it is likely to have some harm. This applies to interventions where the benefits are unknown and the harm – of varying severity – is known. Many complementary therapies fall into this category where the true benefits are largely unknown and the harms are likely to be small.
Consider how the benefits and harms weigh up for you

Every health decision you make – whether about a therapy, diagnostic or screening test, or change in lifestyle – will involve benefits and harms. However, their importance will be valued differently by different people. Your perceptions of what is important in life will affect how you apply the evidence to your own situation.

Apart from personal preferences, you should also consider your level of risk when applying the evidence to yourself. Factors such as age, gender and family history of disease may be important. And remember ‘the five questions’ when making important health decisions. Here they are again:

1. What will happen if I wait and watch?
2. What are my test or treatment options?
3. What are the benefits and harms of these options?
4. How do the benefits and harms weigh up for me?
5. Do I have enough information to make a choice?

**NO**
Get the necessary information and go back to the relevant question

**YES**
Put the best option into action