

The DISCERN Handbook

**Quality criteria for
consumer health information
on treatment choices**

Compiled by
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Preface

Despite a growing investment in consumer health information, the quality of information remains variable. The DISCERN instrument has been developed in recognition of the need for a general set of quality criteria for written consumer health information on treatment choices. DISCERN will enable consumers and information providers to judge the quality of such information. DISCERN can also be used by authors and producers as a guide to the standard of information on treatment choices which consumers are entitled to expect.

The DISCERN Handbook has been developed to ensure that all DISCERN users are able to understand and apply the instrument effectively. The handbook is also a useful resource for education and training among professional and consumer groups on the issues of health information quality, shared decision-making and evidence-based consumer choice.

DISCERN arose from a national project to establish quality thresholds for written information on treatment choices provided by NHS organisations, charities and self-help groups, the pharmaceutical industry and other sources of consumer health information. As the demand for information continues to increase, DISCERN will play a vital role in the delivery of effective healthcare by ensuring that consumers are able to make informed treatment choices based on good evidence. The research team, expert panel and all involved in the development of DISCERN hope it will enable those who use or supply consumer health information to achieve this important goal.

DISCERN Project Team
June 1998

Introduction

DISCERN has been designed to help health consumers and information providers assess the quality of written information about **treatment choices for a health problem**. Although it is unlikely that any one publication can meet all the information needs of a health consumer, there are certain features which should be present if the publication is to be considered useful and appropriate for making decisions about **treatment**. DISCERN consists of 15 questions to help users of consumer health information think about these issues in a systematic way.

Using this handbook

This handbook has been written to help you understand and use DISCERN effectively. It has been written from the perspective of a health consumer (or patient), but can be used by anyone interested in information about treatment choices.

Part 1 describes why the quality of written consumer health information is important and provides some background on the development and use of DISCERN.

Part 2 consists of general instructions which you need to read before using DISCERN.

Part 3 consists of detailed question-by-question instructions and should be used if you are having difficulty rating a question or would like to understand the issues underlying a question more fully. Examples developed from consumer health information are included. The examples are purely fictitious and any resemblance to a real publication is purely coincidental.

Part 4 is the DISCERN instrument.

Part 5 is a quick reference guide to the DISCERN quality criteria for you to use once you are familiar with the instrument.

List of terms

Throughout DISCERN and the handbook, the following terms are used:

Treatment means a course of action adopted to deal with a health problem or illness. Treatments can be *conventional* (or orthodox) or *complementary* (or alternative), and can include *self-care* (or self-help, i.e. ways in which you can help yourself or make yourself feel better) and *psychological* or *emotional* treatments.

Treatment choices refers to the range of possible options for dealing with a health problem and includes both treatments (as listed above) and *no treatment*, i.e. not taking any direct action or using any form of treatment. *No treatment* options include postponing treatment, watchful waiting (monitoring how the condition progresses without treatment) and permanently forgoing treatment.

Outcomes are the short-term and long-term effects of a treatment choice, and include the benefits (or advantages) and risks (or disadvantages) of a treatment choice.

A **publication** is any written document that provides *information about treatment choices* specifically for health consumers. Publications can include books, leaflets, factsheets and newspaper and magazine articles.

Part 1

Background

Clinical effectiveness and evidence-based treatment

Health professionals are increasingly providing treatment based on **evidence of clinical effectiveness**. The evidence consists of rigorous and up-to-date scientific research that has shown the treatment to be largely beneficial. Providing evidence-based treatment involves the constant evaluation of the most effective treatments for a health condition. It often entails replacing established treatments with new or different ones that have been shown to be more effective or safer. Providing evidence-based treatment can also involve the acknowledgement of uncertainty about the most effective treatment, as the quality of clinical evidence can vary or the appropriate research may not have been done.

Consumer choice

The practice of **shared decision-making** is enabling health professionals and consumers to work together to find the best treatment choice for an individual consumer. A vital part of increased consumer involvement in decisions about treatment is access to **good quality information**.

Good quality written consumer health information about treatment choices will be **accurate** and will be based on the best and most **up-to-date scientific evidence**. It will help you consider all aspects of a treatment choice, including the **outcomes** of a treatment choice and any areas of **uncertainty**. It is possible that issues other than clinical effectiveness will also be important when deciding about treatment, and good quality information will help you to **choose the option that is best for you**. Even where there is a clear course of action and your treatment choices are limited, good quality written information will help you to understand your treatment and to know what to expect from treatment.

The DISCERN Instrument

What is DISCERN for?

There is currently a lot of written consumer health information on treatment choices available from a variety of sources. Not all of this information is good quality and only a small proportion is based on good evidence. Many of the publications available provide inaccurate or confusing advice, and it may be hard to know which information to use and which to discard. DISCERN is an instrument, or tool, which has been designed to help users of consumer health information judge the quality of written information about treatment choices.

Who can use DISCERN?

DISCERN is suitable for anyone who uses or produces information about treatment choices. Its uses are diverse and include:

- an aide for **individual consumers** who are making decisions about treatment or who want to know more about a treatment they are using. Consumers, family, friends and carers can use DISCERN to assess the quality of written information and to increase involvement in decisions about treatment by raising issues to discuss with health professionals
- a screening tool for **health information providers**
- a checklist for **authors and producers** of written consumer health information
- a training tool for **health professionals** to improve communication and shared decision-making skills.

How was DISCERN developed?

DISCERN has undergone an extensive process of development and evaluation. A brief summary of the process follows.

We asked an expert panel to analyse a random sample of consumer health information on treatment choices for three medical conditions with varying degrees of evidence: myocardial infarction, endometriosis and chronic fatigue syndrome. A draft instrument based on the panel's analysis was tested by the expert panel on a random sample of new material for the same three conditions. We analysed the performance of the draft instrument using a measure of inter-rater agreement (weighted kappa) and panel debate. The instrument was re-drafted to take account of the results of the analyses. The final pilot of the DISCERN instrument was conducted by a national sample of 13 self-help group members and 15 information providers on a random sample of leaflets from 19 major national self-help organisations. We conducted tests of inter-rater agreement, and participants were asked to complete a questionnaire assessing their views on the validity and applicability of the instrument.

The rigorous process used to develop DISCERN has enabled us to identify a general set of guidelines for the content of written information on treatment choices which can be consistently understood and applied by a wide range of users. Consequently, DISCERN is the first **standardised** index of quality of consumer health information.

What else do I need to know about DISCERN?

Here are some other important details about DISCERN and its use.

Judging the scientific quality or accuracy of written information

DISCERN *cannot* be used to assess the scientific quality or accuracy of the evidence on which a publication is based, as this would require checking against other sources. **DISCERN can be used to judge the reliability of a publication as a source of information about treatment choices.** DISCERN can be used to:

- **assess whether the sources of evidence are explicit.** Question 4 is designed to help you assess whether it is clear where the information about treatment choices has come from. Sources can include research articles, clinical experts and representatives from organisations
- **assess the most common causes of inaccurate or unreliable information** such as whether the publication or the information on which it is based:
 - might not be current (Question 5)
 - is biased (Question 6)
 - fails to refer to a *range* of choices for treatment (Questions 6, 14)
 - cannot be checked (Question 4) or added to (Question 7).

No need for specialist knowledge or help

DISCERN can be used to judge the quality of a publication without the need for specialist knowledge and without reference to other publications or advisers.

You can use DISCERN on your own to judge the quality of a single publication. DISCERN may also raise important issues which will lead you to seek further information or advice, and may be useful for selecting and comparing a range of information about treatment choices.

Rating single treatment publications

DISCERN can be used to judge the quality of publications about one particular treatment choice. It is common for a publication to describe one particular treatment for a health problem. Such publications can provide good quality information as long as it is clear that only one treatment choice is being discussed (Question 1) and that other treatment choices may be available (Questions 6, 14). Apply DISCERN to these publications in the same way as you would to publications about numerous treatment choices: the questions in Section 2 of DISCERN are relevant to a single treatment. Refer to Part 3 of the handbook if you have difficulty.

Presentation

DISCERN is designed to help you rate the quality of a publication in terms of its **content**. We have not included specific questions about the presentation of information (e.g. layout, graphics, readability), as there is already a lot of literature on the importance and use of these features.¹ Furthermore, a publication that is well presented and readable is not necessarily informative and accurate. DISCERN has been developed to fill a gap by examining **what** information a publication is providing, rather than **how** it is providing it.

¹Presentation is an important component in the overall production of good quality information. For more information about presentation and other issues relevant to the production of consumer health information, please contact the Centre for Health Information Quality in Winchester, who will be happy to advise you.

Part 2

General instructions

The questions

DISCERN consists of 15 key questions plus an overall quality rating. Each of the 15 key questions represents a separate **quality criterion** – an essential feature or standard that is an important part of good quality information on treatment choices.

The questions on DISCERN are organised in three sections as follows:

- **Section 1** (Questions 1–8) addresses the reliability of the publication and should help you consider whether it can be trusted as a source of information about treatment choices
- **Section 2** (Questions 9–15) focuses on specific details of the information about treatment choices. Please note:
 - (i) apart from Question 14, the questions are concerned with the treatment choice or choices described *in the publication*, and not with all possible treatment choices
 - (ii) Questions 9 to 11 are concerned with the ‘active’ treatments described in the publication and can include self-care. ‘No treatment’ options are dealt with separately in Question 12
- **Section 3** (Question 16) consists of the **overall quality rating** at the end of the instrument. Your answer to this question should be based on your judgement of the quality of the publication as a source of information about treatment

choices after rating each of the 15 preceding questions, although you should only rate a publication as 'good' quality if it rated well on the majority of the questions. More detailed instructions for rating Question 16 are provided in Part 3 of the handbook.

Occasionally, a question is not appropriate for a publication. For example, the question about no treatment options would not be appropriate for a publication about labour and birth. You should use your judgement to exclude a question that is not relevant. However, DISCERN has been developed as an **appraisal process** and should be used in its entirety. You must not use individual questions or sets of questions separately.

You will find it easiest to read the publication fully before answering the DISCERN questions.

The rating scale

Each question is rated on a 5-point scale ranging from No to Yes. Indicate your answers to each question by circling *one* point on the scale. The rating scale is designed for you to indicate whether the quality criterion in question is present or has been 'fulfilled' by the publication.

General guidelines are as follows:

- **5** should be given if your answer to the question is a definite 'yes' – the quality criterion has been completely fulfilled
- **Partially (2–4)** should be given if you feel the publication being considered meets the criterion in question *to some extent*. How high or low you rate 'partially' will depend on your judgement of the extent of these shortcomings
- **1** should be given if the answer to the question is a definite 'no' – the quality criterion has not been fulfilled at all.

Hints

A number of hints are given after each question. These are designed to provide you with things to look for or consider when deciding your response to a question. The hints should act as a guide rather than as hard and fast rules and your own judgement will also be important.

The rating process is clear-cut for most questions, although more subjective decisions may occasionally be needed. The hints should help you to use your judgement effectively in all cases. More specific instructions are given for Questions 2, 4 and 5.

Additional guidance

Part 3 of the handbook provides additional guidance for rating each question. We have included an example of a Yes, Partially and No rating for each question whenever possible. In some cases, it has not been possible to provide concise examples of the full range of ratings, but you should be able to work out an appropriate response from the instructions and examples given.

Remember: throughout the DISCERN instrument and handbook:

- **treatment** includes self-care
- **treatment choices** are possible treatment options including no treatment
- **information** refers to information about treatment choices only.

Part 3

Instructions for rating
each question

Question 1: Are the aims clear?

What the question is about and why it is important

A good quality publication will have clear aims. A publication should commence with an overview indicating what it is about, what it covers and who it is meant to be for. Clear aims at the beginning of a publication are important because they indicate what aspects of the condition and its treatment will be addressed and help you to judge whether the publication is likely to contain the information you want. It is particularly important to know what may *not* be included, as you may need additional information before you can make an informed decision about treatment.

Rating the question

Examine the opening paragraphs for a description of the content, scope and target audience of the publication. Although the publication's title may be descriptive, the aims should be clearly outlined in the text at the beginning if the publication is to get a good rating.

Guidelines for rating the question:

- **5: Yes** – the publication has clear aims.
- **2–4: Partially** – the publication has aims but they are unclear or incomplete.
- **1: No** – the publication does not include *any* indication of its aims.

Examples

5 rating:

'This booklet has been written to help you understand more about Jones' disease. We hope it answers some of the questions you may have about its diagnosis and treatment. It may also be useful for partners, friends, families and carers and to everyone who is concerned about how Jones' disease affects people and what can be done about it. Occasionally, Jones' disease can affect children. This booklet includes some brief reference to treatment for children but a fuller discussion is outlined in our leaflet entitled Jones' disease in children.'

'Treatments for this condition include dietary advice, drug therapy and surgery. This leaflet has been written for those patients who are considering or have been recommended surgery. It will outline why surgery may have been recommended, what it involves and how it may help you.'

Partially rating:

'This booklet is about some of the treatments for depression.' (No other indication of the aims or contents is provided).

1 rating:

A publication is entitled Treatments for epilepsy but there are no other indications of what the publication is about or who it is written for. The opening paragraph consists of a brief description of the condition and its diagnosis and each subsequent paragraph describes a drug treatment.

Question 2: Does it achieve its aims?

What the question is about and why it is important

A good quality publication will provide the information it has aimed to provide. Question 2 is designed to help you assess whether the information about a treatment choice or choices that was promised at the beginning of the publication has actually been provided. This question is important because a publication that does not achieve its aims is incomplete and you may need more information before you can make a decision about treatment.

Rating the question

After reading the publication, you should refer back to the aims and consider whether all of the information about treatment choices that you were led to expect has been provided.

Guidelines for rating the question:

- **5: Yes** – all the information you were expecting from a description of the aims has been provided.
- **2–4: Partially** – some of the information you were expecting from the aims has been provided.
- **1: No** – *none* of the information you were expecting from the aims has been provided.

If the publication did not have clear aims (rated '1' on Question 1), Question 2 is irrelevant and should not be answered. If aims were outlined but were not clear or were incomplete (rated 'partial' on Question 1), you need to use your judgement to decide what expectations the aims had raised and then rate to what extent those expectations have been fulfilled.

Examples

5 rating:

A leaflet aims to inform consumers about surgical treatments for a condition. The aims indicate that options other than surgery are available (drugs, diet) but that these are not the subject of the publication. In accordance with its aims, the leaflet provides an explanation of why surgery may have been recommended, and describes in detail what it involves and how it may treat the condition.

Partially rating:

A publication aims to provide information about treatment for AIDS, with no mention of any particular focus or omissions. However, the publication provides detailed information about vitamin therapies but does not refer to any other forms of treatment.

1 rating:

A leaflet written for people with a neurological condition aims to help them look after themselves and offers self-help strategies. The leaflet provides a detailed account of the symptoms and diagnosis of the condition, and focuses on employment and benefit rights. The only reference to self-help as a treatment choice is a brief sentence about the importance of avoiding stress, but there is no advice about how this can be done or of the outcomes of any stress management techniques.

Question 3: Is it relevant?

What the question is about and why it is important

A good quality publication will be suited to users' needs. It is important that the information about a treatment choice or choices is relevant to your lifestyle and circumstances. The publication should not make recommendations that are unrealistic or contain assumptions or language that you find inappropriate or offensive.

Rating the question

Your judgement will be very important for rating this question. Your rating can take into account both the content and the presentation of the information about treatment choices.

Guidelines for rating the question:

- **5: Yes** – the information is relevant.
- **2–4: Partially** – the information is relevant to some extent.
- **1: No** – the information is *not at all* relevant.

Examples

5 rating:

You are a middle-aged Asian man with high cholesterol. You have a large family, commute long distances and have very little spare time. Your diet consists of a mixture of Asian and English food. Your GP has given you a leaflet describing self-help treatment for high cholesterol. The leaflet provides dietary recommendations suited to various ethnic groups and tastes that can be easily incorporated into family meals. The leaflet also outlines a simple home-based exercise programme that can be included in your daily routine.

Partially rating:

You are a young person recently diagnosed with diabetes. You work long hours in a manual job and rent a room during the week. You are about to start daily insulin injections and your doctor has given you a booklet written especially for young people with diabetes. The information is technical but it is easy to understand and the style suits you. However, the information about using the treatment, its outcomes and impact on daily life assumes that

all young people will be living at home with family and does not describe the implications of treatment for those living without family support or working.

1 rating:

You are a young pregnant mother with depression who is unsure whether to ask the doctor for some help. You picked up a leaflet written for women with depression at your local child health clinic. The leaflet describes drug therapies. The description of these treatments does not include any discussion of the use of such treatments during pregnancy or breastfeeding. No other treatment choices are mentioned.

You are a single, self-employed businesswoman who travels a lot and you live on your own. You are about to undergo surgery for a gynaecological problem and hope to get back to work quickly. The hospital has provided you with a factsheet about the procedure. However, the author assumes that all readers are married housewives, and discussion of the treatment and post-surgical care outlines the important role of the 'husband' and a return to 'domestic duties' only.

Question 4: Is it clear what sources of information were used to compile the publication (other than the author or producer)?

What the question is about and why it is important

Information about treatment choices should be accurate and based on the best available scientific evidence. DISCERN cannot be used to tell you whether information is true or based on sound evidence, as this would require checking against other sources. However, **a good quality publication will make it clear where the evidence for the information about treatment choices has come from.** Details of the sources of evidence are important, as they enable you to check the information or decide to seek further information. Sources of evidence can include research articles and the opinions of experts such as clinicians and representatives from self-help organisations. The author or producer is not considered a source for this question, as this information is nearly always provided and will not help you discriminate between good and poor quality publications.

Rating the question

There are two parts to the question that are reflected in the hints:

- 1 a main statement or 'fact' about a treatment choice should be accompanied by a reference to the source of evidence in the text in the main part of the publication (e.g. 'Treatment using X has been found to be successful (reference)')
- 2 a source of evidence should be listed in a bibliography or reference list at the end of the publication.

These two parts may not both be present.

It is not possible to make recommendations as to how many statements about treatment choices should be referenced or how many references should be listed at the end of the publication.

Additional sources of support and information provided at the end of the publication, such as 'Further reading' or 'Useful addresses', should not be rated as the sources of evidence for the information about treatment choices. The information provided by 'additional' sources will not necessarily have been used

to compile this publication, and in many cases may provide very different information (*see* Question 7).

Guidelines for rating the question:

- **5: Yes** – the sources of evidence are very clear and the publication enables you to link the source mentioned in the text to a full reference at the end of the publication. It is possible that a publication referring to a single source in both the text and the reference list will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in Question 6.
- **2–4: Partially** – the sources of evidence are clear to some extent. Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or ‘facts’ about treatment choices, although you will need to use your judgement to decide when a reference would be expected.
- **1: No** – no sources of evidence for the information are mentioned.

Remember: a high rating on this question does not mean that the information is accurate or of good scientific quality. It tells you it meets our criterion of the **sources of evidence being explicit**.

It is not yet common practice to include references and therefore it is very unlikely that many publications will rate highly on this question.

Examples

Hint 1 (in the text)

1 (a) *‘In the short-term, treatment X can halt the weight loss associated with Jones’ disease. It can also reduce the symptoms of pain and breathlessness (Jones and Jones, 1995).’*

2 (a) *‘The most common side-effects you may experience with treatment X are sleepiness and slight confusion, but there are no known long-term side-effects or risks associated with this treatment.’⁸*

3 (a) *‘According to the Jones’ Disease Association, patients who decide to postpone treatment do not run any greater risk of lung damage later in life than those opting for early treatment.’*

Hint 2 (in a reference list or bibliography at the end)

1 (b) Jones J, Jones A. The Diagnosis and Management of Jones’ Disease. London: Jones & Co. 1995, 2nd edition.

2 (b) 8 Jones SS. A randomised controlled trial of treatment X for Jones’ disease. Journal of Jones Science, 1998; 3: 11–20.

3 (b) The Jones’ Disease Association, 79 Jones Drive, Jones Town. Tel: 5666 5666.

In each example, a **5** rating is appropriate if both parts (a) and (b) are provided, whilst a **partial** rating will be given if part (a) or part (b) only is provided. If statements or ‘facts’ are presented with no accompanying reference and there is no reference list at the end, the publication will be rated **1**.

Question 5: Is it clear when the information used or reported in the publication was produced?

What the question is about and why it is important

Evidence about effective treatments and choices for treatment can change and it is important that information includes the latest developments in knowledge and practice. DISCERN *cannot* be used to assess how 'up-to-date' the information is, as the rate of change will vary with each medical condition and treatment. However, **a good quality publication will make the date of the information about treatment choices explicit.** An indication of the age of the information is important, as it may lead you to question whether the information is current and to seek further information about the most recent developments.

Rating the question

The hints guide you to look not only for the date the publication itself was produced, but also for the dates of the main sources of evidence used and reported in the publication. The publication cannot be older than the sources of evidence, whereas the sources of evidence can be much older than the publication. Therefore, in order to fulfil the quality criterion for Question 5, the dates for the sources of evidence identified in Question 4 must be clear. A publication that has rated 1 on Question 4 cannot rate high on Question 5.

Hint 1: dates will be found either with the references in the text or in the details of the references in the bibliography or reference list (*see* Examples for Question 4).

Hints 2 and 3: the date of the publication is usually found on the back page of a leaflet or on one of the title pages of a book (usually copyright date). A **revised** publication has been changed or updated since initial publication, and you should use the date for the revised edition to rate the question. It is possible that a publication will not have been revised and therefore Hint 3 can be fulfilled without Hint 2. A **reprinted** publication will not contain new information and you should use the copyright date.

Guidelines for rating the question:

- **5: Yes** – dates for all acknowledged sources are clear.

- **2–4: Partially** – only the date of the publication itself is clear, or dates for *some* but not all acknowledged sources have been given.
- **1: No** – no dates have been given.

Remember: although the dates of the sources may be clear and the publication gets a high rating on this question, it is possible that the information on which the sources are based is not 'up-to-date'. Question 5 will enable you to judge whether the dates are explicit, but not whether the information is current.

It is not yet common practice to include all of these dates and therefore it is very unlikely that many publications will rate highly on this question.

Question 6: Is it balanced and unbiased?

What the question is about and why it is important

A good quality publication will provide fair and impartial information. It is important that information about a treatment choice or choices is presented in a way that enables you to choose what is in *your* best interests. A publication should be honest and informative. It should not influence you by 'promoting' particular treatment choices or by using 'shock tactics'.

Rating the question

Your rating should be based on your impression of the information about treatment choices as a whole. The hints will help you develop a 'feel' for the balance and bias of the information, but your own judgement will also be important. Here are some additional points to help you.

- You should judge the information on its own merits and **you should not be influenced by what you know about the author or producer.** Well-respected individuals (including doctors and charities) can produce poor quality information, and an unknown author or producer can produce information that meets high standards.
- Publications describing **one particular treatment choice** can be acceptable if the author has made this clear (Question 1) and has acknowledged that other treatment choices may be available (Question 14). In all cases, the information about the treatment choice or choices should be drawn from **a range of research and experience.** You should not give a high rating to a publication that relies solely on a single source of evidence or has not revealed any sources (Question 4).
- Ideally, a publication should be **independently reviewed and approved** by an expert, professional organisation or consumer group. Evidence of an external assessment provides readers with some assurance that the information is unprejudiced. However, this is not yet common practice and a publication that omits this information can still achieve a good rating on this question.

Guidelines for rating the question:

- **5: Yes** – the information is completely balanced and unbiased.
- **2–4: Partially** – some aspects of the information are unbalanced or biased.
- **1: No** – the information is completely unbalanced or biased.

Example

1 rating:

A publication describes a single treatment for a skin condition. The publication is written by a doctor and is available through a national self-help organisation. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor's patients who has experienced a 'miraculous' cure. The only reference to other treatment choices is the statement that 'all other treatments for the condition are associated with unacceptable side-effects' and the possibility of 'permanent disfigurement' if no treatment is used. The patient's search for a cure is described as 'torture' that led him to try other treatments that left him 'scarred' and 'suicidal'. The treatment is said to produce 'stunning and permanent results after a few applications with no risks or side-effects'. The author recommends the treatment as 'suitable for anyone' and 'bringing hope to all those who have despaired of finding relief from this devastating and unsightly condition'.

Question 7: Does it provide details of additional sources of support and information?

What the question is about and why it is important

A good quality publication will enable you to find other sources. Details of other sources of support and information about treatment choices are important, as the publication may not provide you with all the information you need and you should be able to trace further information easily.

Rating the question

Additional sources of information and support can be reading materials or other organisations, and are usually listed at the end of the publication under headings such as 'Useful addresses' and 'Further reading'. A reference list or bibliography can also be considered further reading. The details provided should enable you to find the additional sources easily, e.g. name, address and telephone number in the case of an organisation, and author, title, publisher or producer in the case of reading material (and ISBN and date if the material is known to be a book). Many publications provide details of branches of the same organisation. Whilst these may be useful for information about local services, they are unlikely to provide different information about treatment choices, and you should not give a high rating to a publication which only provides these details.

Guidelines for rating the question:

- **5: Yes** – the publication provides full details of *any* additional source other than local branches of the same organisation.
- **2–4: Partially** – the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organisation.
- **1: No** – no additional sources of information are provided.

Examples

5 rating:

Further reading:

Jones J, Jones A. The Diagnosis and Management of Jones' Disease. London: Jones & Co. 1995, 2nd edition. ISBN 000

or

Useful addresses:

The Jones' Disease Association, 79 Jones Drive, Jones Town. Tel: 5666 5666

Question 8: Does it refer to areas of uncertainty?

What the question is about and why it is important

A good quality publication will include a reference to 'grey' areas where there is uncertainty about the most effective treatment. This uncertainty may be because:

- no evidence about effective treatment choices exists
- the existing evidence is contradictory
- there is uncertainty as to who is most likely to benefit or be at risk from the treatment choice.

A good quality publication will highlight the fact that the choice of the most suitable treatment may not be clear-cut and that it may not be possible to predict the most likely outcome for you.

Rating the question

Your judgement will be very important for rating this question. Guidelines for rating the question:

- **5: Yes** – the publication includes a clear reference to *any* uncertainty regarding treatment choices: this may be linked to *each* treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.
- **2–4: Partially** – uncertainty is mentioned but the information is unclear or incomplete.
- **1: No** – no uncertainty about treatment choices is mentioned.

The question cannot be used to assess whether *all* aspects of uncertainty regarding a treatment choice or choices have been covered by the publication (as this would involve checking against other sources).

Examples

5 rating:

'A minority of women will experience side-effects, but it is not always possible to know who these women will be until after treatment has been started.'

'Doctors may give you vague answers to your questions, or may not be able to answer them all. Different doctors may give you different advice. You may be able to find out about the overall success rate of a treatment but doctors may not be able to tell you whether the treatment will definitely work for you. Some people find dealing with this uncertainty difficult. You may find it helpful to discuss your concerns with family or friends or someone from a support group.'

1 rating:

A publication describes a single treatment for a skin condition. The publication is written by a doctor and is available through a national self-help organisation. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor's patients who has experienced a 'miraculous' cure. The only reference to other treatment choices is the statement that 'all other treatments for the condition are associated with unacceptable side-effects' and the possibility of 'permanent disfigurement' if no treatment is used. The patient's search for a cure is described as 'torture' that led him to try other treatments that left him 'scarred' and 'suicidal'. The treatment is said to produce 'stunning and permanent results after a few applications with no risks or side-effects'. The author recommends the treatment as 'suitable for anyone' and 'bringing hope to all those who have despaired of finding relief from this devastating and unsightly condition'.

Question 9: Does it describe how each treatment works?

What the question is about and why it is important

A good quality publication will include information about how a treatment acts on the body and in what way it 'treats' or affects the condition or its symptoms. This may include details of how the treatment is given (or administered). Details of how a treatment works are important, as they enable you to understand a treatment and help you to decide whether it is appropriate for you.

Rating the question

The question is only concerned with the treatment or treatments described in the publication.

Guidelines for rating the question:

- **5: Yes** – the description of *each* treatment includes details of how it works.
- **2–4: Partially** – the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.
- **1: No** – *none* of the descriptions about treatments include details of how treatment works.

Example

5 rating (a single treatment publication):

'Treatment X will stabilise your condition. The treatment is given as a high dosage daily injection over a period of two to three weeks. As the treatment circulates in the blood stream, it reaches cells all over the body and prevents the virus from reproducing and spreading.'

A publication concerned with more than one treatment will be rated 5 if similar descriptions are provided for each treatment mentioned.

Question 10: Does it describe the benefits of each treatment?

What the question is about and why it is important

A good quality publication will describe the benefits of each treatment. Most treatments have some benefits or advantages. It is important to be aware of the benefits so that you know what to expect from a treatment and can decide whether it is associated with an outcome that is important for you.

Rating the question

The question is only concerned with the treatment or treatments described in the publication, and simply requires you to rate whether *any* benefit is mentioned for *each* of the treatments described. The question is not concerned with the size of the benefit or who is most likely to benefit. The question cannot be used to assess whether *all* of the benefits associated with each treatment have been described as this would involve checking against other sources.

Guidelines for rating the question:

- **5: Yes** – a benefit is described for *each* treatment.
- **2–4: Partially** – a benefit is described for some but not all of the treatments.
- **1: No** – no benefits are described for any of the treatments.

Examples

5 rating (a single treatment publication):

'For most people, the treatment will provide a complete cure within a few weeks.'

'In the short-term, treatment X can halt the weight loss in sufferers from Jones' disease. It can also reduce the symptoms of pain and breathlessness. Whilst it cannot cure the condition, treatment X can provide long-term stabilisation and will prevent the condition from worsening.'

A publication concerned with more than one treatment will be rated **5** if similar descriptions are provided for each treatment mentioned.

Question 11: Does it describe the risks of each treatment?

What the question is about and why it is important

A good quality publication will describe the risks of each treatment. Most treatments involve some risks or disadvantages. It is important to be aware of the risks so that you know what to expect from a treatment and can decide whether it is associated with an outcome that is important for you.

Rating the question

The question is only concerned with the treatment or treatments described in the publication, and simply requires you to rate whether *any* risk is mentioned for *each* of the treatments described. The question is not concerned with the size of the risk or who is most likely to be at risk. The question cannot be used to assess whether *all* of the risks associated with each treatment have been described as this would involve checking against other sources.

Guidelines for rating the question:

- **5: Yes** – a risk is described for *each* treatment.
- **2–4: Partially** – a risk is described for some but not all of the treatments.
- **1: No** – no risks are described for any of the treatments.

Examples

5 rating (a single treatment publication):

'Side-effects include dizziness, muscle pain and insomnia.'

'The research revealed the main side-effects were generally mild and reversible and included a dry mouth and nausea. The treatment did not seem to have a harmful effect on any major organs when taken over a short period. However, some users developed kidney problems after prolonged use and the treatment should be carefully monitored.'

A publication concerned with more than one treatment will be rated 5 if similar descriptions are provided for each treatment mentioned.

Question 12: Does it describe what would happen if no treatment is used?

What the question is about and why it is important

A good quality publication will include a description of what would happen if the condition is left 'untreated'. It is important to be aware of the outcomes of not using any treatment so that you know what to expect and can decide whether not using any treatment is associated with an outcome that is important for you.

Rating the question

The question simply requires you to rate whether *any* outcome associated with not using treatment is mentioned. The question is not concerned with the size of the risks or benefits or who is most likely to be at risk or to benefit from no treatment options. It is not possible to assess whether *all* the risks or benefits of each no treatment option have been described as this would involve checking against other sources.

Guidelines for rating the question:

- **5: Yes** – there is a clear description of a risk *or* a benefit associated with *any* no treatment option.
- **2–4: Partially** – a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.
- **1: No** – the publication does not include any reference to the risks or benefits of no treatment options.

Examples

5 rating:

'You may decide that none of the treatments described would suit you and that you would rather wait to see what happens without treatment. Although your symptoms may cause you some discomfort and you may want to consider some pain control techniques, the condition should not worsen and there are no major disadvantages associated with not using treatment.'

'Many women with Jones' disease may safely put off treatment until there is no longer any chance of them becoming pregnant. However, treatment at some stage is recommended, as it

becomes less effective after the menopause and there is a risk of lung damage if no treatment is used.'

'This is a rapidly progressing, life-threatening condition and early treatment is recommended. Unfortunately, delaying treatment can result in long-term damage to the heart.'

Question 13: Does it describe how the treatment choices affect overall quality of life?

What the question is about and why it is important

A good quality publication will include a description of the broader aspects of treatment choices – not just risks and benefits, but the overall impact of a treatment choice or choices on day-to-day living. This question is important because a treatment choice may involve major changes in lifestyle or circumstances or have important effects on those close to you that you need to be aware of and consider before making a decision.

Rating the question

This question is only concerned with the treatment choices outlined in the publication. No treatment options are included as a treatment choice for this question if Question 12 was rated above 1.

Guidelines for rating the question:

- **5: Yes** – the publication includes a clear reference to overall quality of life in relation to *any* of the treatment choices mentioned.
- **2–4: Partially** – the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.
- **1: No** – there is no reference to overall quality of life in relation to treatment choices.

Examples

5 rating:

'Patients are monitored continuously in hospital for a week before the procedure is carried out, and recovery time can vary from several days to several weeks. If you are undergoing this form of treatment, you may need to take a lot of time off work and to have someone to care for you when you come home.'

'Because Treatment X is normally given as a course of injections, you will need to visit your GP's surgery daily throughout the weeks of treatment. As there is a slight risk of fainting

during the initial stages of treatment, you need to ensure that your family and work mates are able to look out for you, and you will not be able to drive or operate heavy machinery.'

'You may feel depressed and confused for a while following surgery. You may feel that you are not the same person and that you can no longer achieve or enjoy the things you used to. Take time to adjust to your new physique and to get used to a few limitations on your physical activity.'

Question 14: Is it clear that there may be more than one possible treatment choice?

What the question is about and why it is important

A good quality publication will indicate that there is a choice about treatment.

The publication should indicate that the treatment choices described may be suited to some people more than others, and that there is nearly always a *choice* of treatment, even if a full account of alternatives has not been presented in the publication.

Rating the question

Your judgement will be important for rating this question. Consider the publication as a whole and use the hints to help you decide whether it has highlighted the issue of treatment choice for each consumer or patient.

Guidelines for rating the question:

- **5: Yes** – the publication makes it very clear that there may be more than one possible treatment choice.
- **2–4: Partially** – the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.
- **1: No** – the publication does not give any indication that there may be a *choice* about treatment.

Examples

5 rating:

A publication provides information about a new treatment for a form of cancer. The treatment is reported to be the most effective treatment available for the majority of people with this condition, and the authors describe the factors known to be associated with good treatment outcomes (such as treatment at an early stage of the disease and the absence of other medical conditions). The authors highlight some unpleasant short-term side-effects associated with the treatment and the possibility that a minority of patients may experience serious long-term consequences as a result of treatment, including the development of other cancers. A brief description of the natural progress of the disease and what is likely to

happen without any treatment is also included. Other treatments are mentioned briefly and the authors refer readers to several other publications for more details. The authors conclude that they cannot recommend what would be best for an individual patient.

1 rating:

A publication describes a single treatment for a skin condition. The publication is written by a doctor and is available through a national self-help organisation. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor's patients who has experienced a 'miraculous' cure. The only reference to other treatment choices is the statement that 'all other treatments for the condition are associated with unacceptable side-effects' and the possibility of 'permanent disfigurement' if no treatment is used. The patient's search for a cure is described as 'torture' that led him to try other treatments that left him 'scarred' and 'suicidal'. The treatment is said to produce 'stunning and permanent results after a few applications with no risks or side-effects'. The author recommends the treatment as 'suitable for anyone' and 'bringing hope to all those who have despaired of finding relief from this devastating and unsightly condition'.

Question 15: Does it provide support for shared decision-making?

What the question is about and why it is important

A good quality publication will raise issues for you to discuss with all those involved in your care about the best treatment choice for *you*. The information about a treatment choice or choices provided by the publication should enable you to prepare for a consultation with a health professional or to talk through issues that might affect your family, friends or carers regarding *your* treatment choices.

Rating the question

Consider the publication as a whole and decide whether it has enabled you to prepare a list of specific issues to consider and discuss concerning *your* treatment choices. These issues should be made clear throughout the publication, rather than merely being queries arising from its deficiencies and gaps. How high you rate the publication will depend on your judgement of how much it will support you in sharing decisions about treatment choices. If you do not wish to share in decision-making about your treatment, rate the publication from the point of view of a carer or relative who wants to know more about your treatment choices.

Guidelines for rating the question:

- **5: Yes** – the publication provides very good support for shared decision-making.
- **2–4: Partially** – the publication provides some support for shared decision-making.
- **1: No** – the publication does not provide *any* support for shared decision-making.

Examples

Issues to consider and discuss are usually presented at various points throughout the publication. Here are some simple examples:

5 rating:

'You may want to know whether your treatment will work or whether you can stay well without treatment. Your partner or carer may also have a lot of concerns and questions

about how they can help you and how your condition and treatment will affect them. Try to find out as much as you can about your treatment options and make a list of questions you want to ask your doctor.'

'Treatment can last several years and you are advised not to get pregnant during this time. If you had planned to have a baby soon or are worried about contraception, you should talk to your doctor before you start treatment. If you have a partner, try to discuss these issues together with your doctor.'

Question 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

What the question is about and why it is important

Question 16 is an 'intuitive summary' of your responses to the preceding 15 questions. All publications will have deficiencies, and it is unlikely that any one publication will rate high on all of the questions. However, after completing all of the questions on DISCERN, you should have developed some feeling for the overall quality of the publication which will help you decide whether it is a useful and appropriate source of information about your treatment choices.

Rating the question

The guidelines below should help you to rate this question, but your judgement is also very important. It may encourage you to know that during the development and testing of the instrument, users independently reached very similar conclusions about the overall quality of the publications they were rating even though we did not provide very specific instructions for this question. DISCERN has been designed to help you develop your critical skills, so trust your own opinion!

Guidelines for rating the question:

- **High (5)** – the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is 'good' quality – it is a useful and appropriate source of information about treatment choices.
- **Moderate (3)** – the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is 'fair' quality – it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.
- **Low (1)** – the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is 'poor' quality – it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

Part 4

The DISCERN instrument

Organisations are authorized to reproduce The DISCERN Instrument without permission, provided (a) it is used in accordance with the instructions contained in this Handbook to ensure that its methodology is uniform and (b) that their experience in using it is summarized on the evaluation form provided at the end of the Handbook. A copy of this evaluation should then be sent to Radcliffe Medical Press Ltd, 18 Marcham Road, Abingdon, Oxon OX14 1AA (Fax: 01235 528830) for assessment by the NHS Research & Development Programme as part of The DISCERN Project's future development.

DISCERN

**An instrument for judging the quality
of written consumer health information on
treatment choices**

Funded by The British Library

For further information please contact:

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Institute of Health Sciences

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Section I

IS THE PUBLICATION RELIABLE?

1 Are the aims clear?

No		Partially		Yes
1	2	3	4	5

HINT Look for a clear indication at the beginning of the publication of:

- what it is about
- what it is meant to cover (and what topics are meant to be excluded)
- who might find it useful.

If the answer to Question 1 is 'No', go directly to Question 3

2 Does it achieve its aims?

No		Partially		Yes
1	2	3	4	5

HINT Consider whether the publication provides the information it aimed to as outlined in Question 1.

3 Is it relevant?

No		Partially		Yes
1	2	3	4	5

HINT Consider whether:

- the publication addresses the questions that readers might ask
- recommendations and suggestions concerning treatment choices are realistic or appropriate.

4 Is it clear what sources of information were used to compile the publication (other than the author or producer)?

No		Partially		Yes
1	2	3	4	5

HINT

- Check whether the main claims or statements made about treatment choices are accompanied by a reference to the sources used as evidence, e.g. a research study or expert opinion.
- Look for a means of checking the sources used such as a bibliography/reference list or the addresses of the experts or organisations quoted.

Rating note: In order to score a full '5' the publication should fulfil both hints. Lists of *additional* sources of support and information (Q7) are not necessarily sources of *evidence* for the current publication.

5 Is it clear when the information used or reported in the publication was produced?

No		Partially		Yes
1	2	3	4	5

HINT Look for:

- dates of the main sources of information used to compile the publication
- date of any revisions of the publication (but not dates of reprinting)
- date of publication (copyright date).

Rating note: The hints are placed in order of importance – in order to score a full '5' the dates relating to the first hint should be found.

6 Is it balanced and unbiased?

No		Partially		Yes
1	2	3	4	5

HINT Look for:

- a clear indication of whether the publication is written from a personal or objective point of view
- evidence that a *range* of sources of information was used to compile the publication, e.g. more than one research study or expert
- evidence of an external assessment of the publication.

Be wary if:

- the publication focuses on the advantages or disadvantages of one particular treatment choice without reference to other possible choices
- the publication relies primarily on evidence from single cases (which may not be typical of people with this condition or of responses to a particular treatment)
- the information is presented in a sensational, emotive or alarmist way.

7 Does it provide details of additional sources of support and information?

No		Partially		Yes
1	2	3	4	5

HINT Look for suggestions for further reading or for details of other organisations providing advice and information about the condition and treatment choices.

8 Does it refer to areas of uncertainty?

No		Partially		Yes
1	2	3	4	5

HINT

- Look for discussion of the gaps in knowledge or differences in expert opinion concerning treatment choices.
- Be wary if the publication implies that a treatment choice affects everyone in the same way, e.g. 100% success rate with a particular treatment.

Section 2

HOW GOOD IS THE QUALITY OF INFORMATION ON TREATMENT CHOICES?

N.B. The questions apply to the treatment (or treatments) described in the *publication*. Self-care is considered a form of treatment throughout this section.

9 Does it describe how each treatment works?

No		Partially		Yes
1	2	3	4	5

HINT Look for a description of how a treatment acts on the body to achieve its effect.

10 Does it describe the benefits of each treatment?

No		Partially		Yes
1	2	3	4	5

HINT Benefits can include controlling or getting rid of symptoms, preventing recurrence of the condition and eliminating the condition, both short-term and long-term.

11 Does it describe the risks of each treatment?

No		Partially		Yes
1	2	3	4	5

HINT Risks can include side-effects, complications and adverse reactions to treatment, both short-term and long-term.

I2 Does it describe what would happen if no treatment is used?

No		Partially		Yes
1	2	3	4	5

HINT Look for a description of the risks and benefits of postponing treatment, of watchful waiting (i.e. monitoring how the condition progresses without treatment) or of permanently forgoing treatment.

I3 Does it describe how the treatment choices affect overall quality of life?

No		Partially		Yes
1	2	3	4	5

HINT Look for:

- description of the effects of the treatment choices on day-to-day activity
- description of the effects of the treatment choices on relationships with family, friends and carers.

I4 Is it clear that there may be more than one possible treatment choice?

No		Partially		Yes
1	2	3	4	5

HINT Look for:

- a description of who is most likely to benefit from each treatment choice mentioned, and under what circumstances
- suggestions of alternatives to consider or investigate further (including choices not fully described in the publication) before deciding whether to select or reject a particular treatment choice.

15 Does it provide support for shared decision-making?

No		Partially		Yes
1	2	3	4	5

HINT Look for suggestions of things to discuss with family, friends, doctors or other health professionals concerning treatment choices.

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

Low		Moderate		High
<i>Serious or extensive shortcomings</i>		<i>Potentially important but not serious shortcomings</i>		<i>Minimal shortcomings</i>
1	2	3	4	5

Part 5

Quick reference guide to the DISCERN criteria

A good quality publication about treatment choices will:

- 1 Have explicit aims
- 2 Achieve its aims
- 3 Be relevant to consumers
- 4 Make sources of information explicit
- 5 Make date of information explicit
- 6 Be balanced and unbiased
- 7 List additional sources of information
- 8 Refer to areas of uncertainty
- 9 Describe how treatment works
- 10 Describe the benefits of treatment
- 11 Describe the risks of treatment
- 12 Describe what would happen without treatment
- 13 Describe the effects of treatment choices on overall quality of life
- 14 Make it clear there may be more than one possible treatment choice
- 15 Provide support for shared decision-making

This guide should only be used once you are acquainted with the full DISCERN instrument.

EVALUATION

Organisations are authorized to reproduce The DISCERN Instrument without permission, provided (a) it is used in accordance with the instructions contained in this Handbook to ensure that its methodology is uniform and (b) that their experience in using it is summarized on this evaluation form. A copy of this evaluation should then be sent to Radcliffe Medical Press Ltd, 18 Marcham Road, Abingdon, Oxon OX14 1AA (Fax: 01235 528830) for assessment by the NHS Research & Development Programme as part of The DISCERN Project's future development.

1 What have you used DISCERN for?

(You may tick more than one)

- Assessing information for **professional** purposes
(i.e. for an organisation or as part of my job)
- Assessing information for my own **personal** use
- Producing information
- Other (please specify)

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2 What do you like about DISCERN?

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Continued overleaf

3 What issues has DISCERN raised for you as an individual or member of an organisation?

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4 Any other comments?

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Your name _____

Job title (if relevant) _____

Organisation _____

Address _____

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