

DISCERN Genetics Quality Criteria

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The Rating Scale

Each question is rated on a 5 point scale ranging from No to Yes. Show your answer to each question by circling one point on the scale. The rating scale is designed to help you assess if the quality criteria in the questions are present or have been 'fulfilled' by the publication.

General guidelines are as follows:

- 5 should be given if your answer to the questions is a definite 'yes' – the quality criterion has been completely fulfilled
- Partially (2-4) should be given if you feel the information being considered meets the criterion in the question to some extent. How high or low you rate 'partially' will depend on your judgment 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 to each question. These are designed to provide you with things to 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 judgment will also be important.

Question 20 is the overall quality rating at the end of the questionnaire. Your answer to this question should be based on your judgment of the quality of the publication as a source of information about treatment choices after rating each of the preceding 19 questions. However, you should only rate a publication as good quality if it rated well on the majority of questions.

You may find it easiest to read the information fully before answering the DISCERN Genetics questions.

DISCERN Genetics Quality Criteria

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1. Are the aims clear?				
No		Partially		Yes
1	2	3	4	5

Hint: Look for a clear indication in the information of

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

Note: It may be necessary to search for the aims especially in web based information

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 if it provides the information it aimed to, as outlined in question 1

3.	Is there an explanation on the background and effects of the condition?				
No		Partially			Yes
1	2	3	4	5	

Hint: Look for a description of the condition, which may include

- the problems it can cause
- who it affects
- the symptoms
- how common it is
- how often it occurs in different populations
- an explanation of how the condition runs in a family
- a description of the difference between being a carrier¹ and having the condition
- a description of the predicted course of the condition
- details of any complications

4.	Are treatment and management choices for the condition described?				
No		Partially			Yes
1	2	3	4	5	

Hint: Look for information on

- how the condition is treated
- any procedure for referral to a specialist
- how symptoms can be reduced
- how well the treatment works
- a description of possible complications of treatment
- any implications for having children
- other interventions available e.g. prophylactic mastectomy², termination of pregnancy

¹ Each person carries two copies of every gene. In a recessive condition BOTH copies of the gene must be altered to cause the condition or disease. If a person has an alteration in only one of the recessive genes that person will not have the condition in question but may pass the altered gene onto their children. This person is called a CARRIER

² This is an operation to remove all breast tissue in women who are at high risk of developing breast cancer due to a hereditary cause. The removal of breast tissue reduces the risk of developing breast cancer in these women.

10. Does the information state who will have access to the test results?

No			Partially		Yes
1	2	3	4	5	

Hint: Does it describe who will have access to your test results e.g. other health care professionals

11. Does the information 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 testing and screening

12. Are issues of discrimination discussed?

No			Partially		Yes
1	2	3	4	5	

Hint: Does the information describe the implications of discrimination arising from the test result, especially on insurance and employment issues

13. Does the information acknowledge the psychosocial consequences of being tested for the condition?

No			Partially		Yes
1	2	3	4	5	

Hint: Check whether the information takes into account

- the emotional consequences
- the social consequences
- the fact that the test may increase anxiety
- that a range of reactions are possible and normal

14. Are the consequences of genetic testing and screening for the relatives and partner of the person being tested discussed?

No		Partially		Yes
1	2	3	4	5

Hint: Check whether the information takes into account

- what being at increased risk might mean to the person being tested and their family
- the emotional consequences for the family
- the implication for relationships e.g. embarrassment, shame, anger, and strained relationships may all be normal outcomes
- that different people have different reactions
- that misattributed paternity⁹ may be discovered

⁹Genetic tests sometimes reveal that the man who is thought to be the child's father is not the child's biological father.

15. Does it provide details of additional sources of support and information?

No		Partially		Yes
1	2	3	4	5

Hint: Look for links to other sources of information, e.g. references in the text, websites, other literature, telephone numbers, postal addresses, help lines, support groups, other health professionals.

16. Is it clear what sources of information were used to compile the publication?

No		Partially		Yes
1	2	3	4	5

Hint: Check whether the main claims or statements are accompanied by a reference to the sources used as evidence. Look for

- a means of checking the sources used such as a bibliography, a list of references or addresses of any experts or organisation quoted
- a reference to a current guideline on which the information is based

17. 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
- the date of the publication and any revision
- an updating policy – particularly on internet sites

18. Is the information balanced and unbiased?					
No			Partially		Yes
1	2	3	4	5	

Hint: Look for

- a clear indication of whether the information 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
- a statement of the affiliation of the author

Be wary if

- the information focuses on the advantages or disadvantages of one particular test without reference to other possible choices
- the information relies primarily on evidence from a single case which may not be typical of people with the condition
- the tone of the information is inappropriate e.g. it is presented in an sensational, emotive or alarmist way

The following question may not be relevant to all information. If this is the case please circle Not Applicable (N/A).

19. Is information provided on local availability of services and test performance?					
No			Partially		Yes
1	2	3	4	5	N/A

Hint: Look for any geographical relevance

- are any geographical differences in service provision outlined e.g. test availability
- does it have to be paid for privately or is it free

20. Based on the answers to all of the above questions, rate the overall quality of the information as a source of information about genetic testing and screening				
Low		Moderate		High
Serious extensive shortcomings		Potentially important but not serious shortcomings		Minimal shortcomings
1	2	3	4	5

