European Journal of Human Genetics (2006) 14, 1179–1188

www.nature.com/ejhg

ARTICLE

# DISCERN-Genetics: quality criteria for information on genetic testing

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**Information currently available to the public is inadequate to support those deciding to consent to a genetic test. As genetic knowledge continues to evolve, more people will be forced to consider the complex issues raised by genetic testing. We developed and tested criteria to guide the production and appraisal of information resources produced for the public on genetic testing. Lay people with and without experience of a genetic condition, and providers and producers of health information appraised and listed the criteria they used to rate the quality of a sample of information on cystic fibrosis, Down's syndrome, familial breast cancer, familial colon cancer, haemochromatosis, Huntington's disease, sickle cell disease, and thalassaemia. These genetic conditions represent different populations, disease pathways, and treatment decisions. The information medium could be written, electronic, CD, audio or video. The quality criteria were tested iteratively (using the weighted kappa statistic) for the level of agreement between users applying successive drafts of the criteria to different samples of information. The final set of criteria consisted of 19 questions plus an overall quality rating. Chance corrected agreement (weighted kappa) among the appraisers for the overall quality rating was 0.61 (0.60–0.62). The criteria cover the scope of the information resources, information on the condition, the test procedure and results, decision making, and the reliability of the information. The DISCERN-Genetics criteria will guide the production and appraisal of information produced for the public, and will facilitate the involvement of the public in decisions around genetic screening and testing.**
*European Journal of Human Genetics* (2006) **14,** 1179–1188. doi:10.1038/sj.ejhg.5201701; published online 26 July 2006

**Keywords:** genetic screening and testing; information

## Introduction

Participating in decisions about health care is impossible without adequate information, and yet poor quality information is repeatedly described across a range of health topics.[1] Recently, this has become a concern with the delivery of genetic services.[2,3] As more mutations are identified, and the availability and relevance of genetic tests to clinical practice increases, the public will rely on diverse clinical services and mass media sources for information about the use and consequences of genetic technology.[4] Criteria to assess the quality of information will provide clinicians with a mechanism for involving

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**Received 20 January 2006; revised 13 June 2006; accepted 15 June 2006; published online 26 July 2006**

patients in decisions about genetic testing,[5] make explicit the gaps in available information, and will help the public use available resources.

Robust methods for appraising and integrating evidence into clinical decision making are widely available,[6] whereas methods for appraising information produced for the public are still being developed.[7] Quality criteria or rating schemes exist, but tend to focus on general aspects of quality,[8,9] and have been produced through the consensus of experts or feedback from patients or the public rather than using an empirical approach to test for reliability or validity.[10] The DISCERN criteria for appraising information on treatment have good levels of inter-rater agreement and validity, and provide a framework for assessing the evidence base of lay health information.[11,12] The criteria are widely used as a benchmark to appraise[13–17] and guide the production of lay health information on treatment,[18,19] have been used to train health professionals in appraisal skills in a variety of settings,[20–22] and have been translated into five languages. The need for high-quality information that deals with the complex issues raised by genetic testing will increase as genetic knowledge continues to evolve. We followed the DISCERN methodology (described below) to develop criteria to assess the quality of information produced for the public on genetic screening and testing.

## Materials and methods

We recruited providers and producers of genetic information, and lay people with and without experience of a genetic condition (see Box 1) to appraise a sample of information on genetic screening and testing.

**Box 1** Appraisers

| |
|---|
| Clinical geneticists (2) |
| Genetic counselors (2) |
| General Practitioner |
| Journalist (science writer) |
| Lay members with experience of a genetic condition (3) |
| Lay member with no experience of a genetic condition |
| Medical ethicist |
| Midwife |
| Obstetrician |
| Producers of information (2) |

We collected information on the following genetic conditions: cystic fibrosis, Down's syndrome, familial breast cancer, familial colon cancer, haemochromatosis, Huntington's disease, sickle cell disease, and thalassaemia. The conditions were selected to include different populations, different disease pathways, and treatment decisions (see Flow Chart).

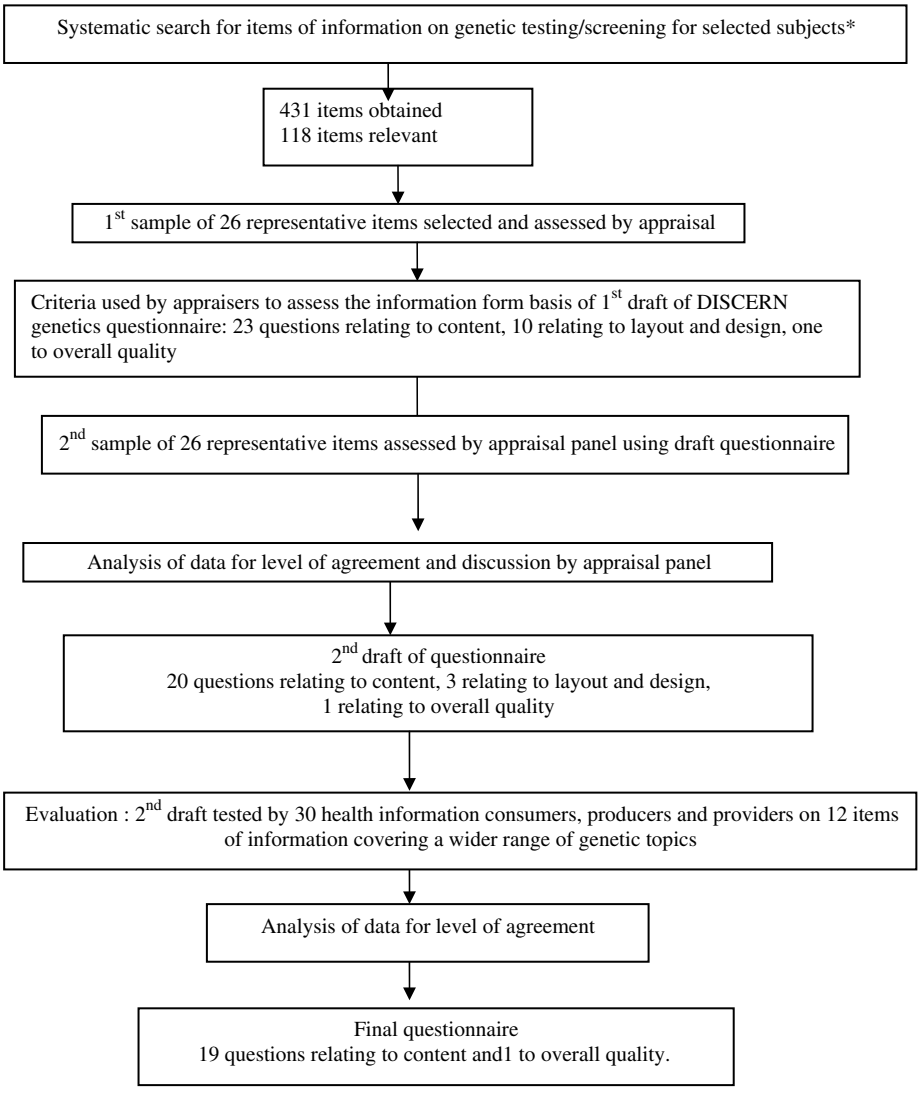
### Sources of information

During 2003/2004, we collected information in English in a variety of forms (written, online, CD, audio, and video) from voluntary organisations, charities, commercial publishers, professional associations, individual health-care professionals, and NHS Trusts. Organisations were identified through professional associations (Sickle Cell and Thalassaemia Societies and Haemoglobinopathy Centres in the UK), the Genetic Interest Group {http://www.gig.org.uk/} for Clinical Genetic Centres and Voluntary Organisations, GeneWatch UK (for information on manufacturers of gene testing kits), registries and databases (Birth Choice UK for Midwifery Departments, the Popular Medical Index,[23] COPAC (www.copac.ac.uk), and the internet for online booksellers (www.amazon.co.uk; http://bookshop.blackwell.co.uk/jsp/welcome.jsp www.thebookplace.com); videos {www.videosforpatients.co.uk/; http://www.emol.ac.uk; http://library.wellcome.ac.uk/}; newspapers (http://bubl.ac.uk/link/n/newspapers.htm); and support groups. In addition, meta search engines (http://www.surfwax.com; http://www.ixquick.com), Google, and health information portals were used to identify relevant material. Initially, we searched for information using the terms patient information/genetic testing/genetic screening combined with terms for the specific conditions; we then broadened our search by using terms for each of the conditions. We also contacted the BBC Information and Archives service, Channel 5, and the Digital Discovery Health Channel.

We obtained 431 items of information from these searches, 19 of these were duplicates, and only 118 were relevant, that is, they specifically described an aspect of genetic screening and testing related to one of the conditions. VG, PR, and SS reviewed the 118 items of information and selected 26 to represent each of the conditions in a variety of formats (one book, one book chapter, one video, 13 web pages, 10 leaflets), from different producers (public and commercial) and country of origin.

### First appraisal

We sent copies of the 26 items of information to each of the appraisers to critique using their individual experience and expertise. Having completed the task, they were asked to list and explain the criteria they used; they had 6 weeks to complete the exercise. We (VG/PR/SS) independently sorted the criteria into common themes,[24] which were turned into questions. Criteria related to each question were written as hints to help the user apply the questions. This was carried out iteratively until consensus was reached. The appraisers met to discuss the results of the initial analysis, the meeting was chaired by SO, audio-taped, and transcribed.




* Cystic fibrosis, Down syndrome, familial breast cancer, familial colon cancer, haemochromatosis, Huntington's disease, sickle cell disease, and thalassaemia.

### Testing the questionnaire

Following the meeting, the appraisers independently applied the resulting questionnaire to a new sample of 26 items of information about the same conditions (one book chapter, one interactive CD, two newspaper/magazine articles, 11 web pages, 11 leaflets). They had 6 weeks to complete the exercise. We analysed the data using a measure of inter-rater agreement (see Statistical analysis). The appraisers met again to discuss the results of the analysis and to re-draft the questionnaire for areas where there was poor agreement; as before, the meeting was chaired by SO. Questions were modified or excluded if they produced agreement scores below an acceptable level ($k<0.40$) (see Statistical analysis) or they represented overlapping themes.

### Evaluation of the DISCERN_GENETICS questionnaire

Thirty participants who dealt with health information in a professional capacity, or were users of health information, applied the revised questionnaire to 12 items of information covering a wider range of conditions requiring genetic screening and testing. The inter-rater agreement was tested (see Statistical analysis).

## Statistical analysis

We tested the reliability of the questionnaire at each phase by calculating agreement between raters for each DISCERN item using $\kappa$ with quadratic weights, a chance corrected measure of agreement. Weighted $\kappa$ is appropriate for the analysis of data in ordered categories, such as the five-point

Likert scale used to rate each DISCERN item, because it does not treat all disagreements equally. Different weights are given to disagreements between raters according to the magnitude of the discrepancy. In the case of multiple raters, weighted $\kappa$ is calculated by generating a $\kappa$ score for each possible pair of raters for each item being rated. An overall $\kappa$ score is then generated by calculating the average of these individual $\kappa$ with an appropriate overall standard error. The cutoff point for an acceptable level of agreement with multiple raters was set at $\kappa \geqslant 0.4$.[25]

### Sample size

A sample size of 390 rated articles (15 raters $\times$ 26 articles) was selected for the appraisers, to produce confidence intervals for weighted kappa with a width of less than 0.1.

## Results

The first draft of the questionnaire had 26 questions related to the content of information and 10 to layout and design. Each question was followed by a hint or prompt question, which was taken verbatim from the criteria generated by the appraisers and represented specific aspects of each question.

### First meeting of the appraisers

During the first meeting, the 26 questions were refined to 23, each rated on a five-point Likert scale (1 = no, the criteria has not been filled, and 5 = yes, the criteria has been filled). A question rating the overall quality of the publication was added to the end of the questionnaire, with the instruction that the rating of overall quality should be based on responses to the previous questions.[11]

### Testing of the draft questionnaire

The level of agreement for the questions related to layout and design was poor ($\kappa$ 0.11–0.24); eight of the content questions achieved $\kappa$ scores $>0.4$, including the rating for overall quality ($\kappa = 0.44$, 95% CI 0.41–0.46) (see Table 1).

### Second meeting of the appraisers

During the second meeting, the questionnaire was re-drafted, incorporating the results of the analysis. Modifications consisted of rewording questions if the level of agreement was poor ($<0.4$) and merging some of the overlapping questions ('uncertainty in testing' was combined with 'test accuracy'; and 'informed decision making' with 'shared decision making'). The wording for the risk criterion was one area where it was difficult to reach agreement. Discussions explored the concepts behind a summary estimate of risk, and increased risk. The initial question asked if a summary of risk was explained, this was changed to 'Is risk explained in simple terms' as there was no agreement on the best way to present risk information. The appraisers recommended that no items were dropped, and a 'not applicable' box was added to a question about information on the local availability of services. Instructions to guide the user were made clearer, and it was agreed to draft a glossary of genetic terms to accompany the questionnaire. The re-drafted questionnaire consisted of 19 questions plus the overall quality rating. The appraisers strongly advocated that the 10 questions on layout and design were reduced to three questions covering read-

**Table 1** Summary of agreement from each testing of the DISCERN-Genetics questionnaire

| *Question theme* | *Kappa score from appraisers (95% CI)* | *Kappa score from evaluation (95% CI)* |
|---|---|---|
| Aims are clear | 0.37 (0.34–0.40) | 0.43 (0.42–0.45) |
| Aims achieved[a] | 0.19 (0.16–0.23) | 0.25 (0.23–0.27) |
| Background of the condition | 0.38 (0.35–0.41) | 0.63 (0.62–0.65) |
| Treatment choices | 0.29 (0.26–0.32) | 0.42 (0.40–0.44) |
| Risk | 0.24 (0.21–0.27) | 0.59 (0.58–0.60) |
| Purpose of the test | 0.22 (0.19–0.25) | 0.46 (0.45–0.48) |
| Testing procedure | 0.38 (0.35–0.41) | 0.48 (0.46–0.49) |
| Test accuracy | 0.38 (0.35–0.41) | 0.49 (0.47–0.50) |
| After the test | 0.45 (0.42–0.48) | 0.43 (0.41–0.45) |
| Access to test results | 0.36 (0.33–0.40) | 0.44 (0.43–0.46) |
| Shared decision making | 0.33 (0.30–0.36) | 0.51 (0.49–0.52) |
| Discrimination | 0.76 (0.74–0.79) | 0.74 (0.73–0.76) |
| Psychosocial consequences | 0.69 (0.67–0.72) | 0.75 (0.74–0.77) |
| Consequences for others | 0.64 (0.61–0.67) | 0.58 (0.57–0.60) |
| Additional sources of information | 0.50 (0.47–0.52) | 0.59 (0.58–0.61) |
| Sources of information used | 0.47 (0.44–0.50) | 0.53 (0.51–0.55) |
| Date of the information | 0.44 (0.42–0.47) | 0.39 (0.37–0.41) |
| Balance and bias | 0.33 (0.30–0.36) | 0.47 (0.45–0.48) |
| Local information[b] | 0.24 (0.21–0.27) | 0.25 (0.23–0.27) |
| Overall quality | 0.44 (0.41–0.46) | 0.61 (0.60–0.62) |

[a]If the answer to question 1 was 'no' raters were instructed not to answer Question 2.
[b]Not applicable added to this question.

ability, language, and style and structure. These questions were retested by seven of the appraisers and the level of agreement remained poor ($\kappa = 0.14$; $\kappa = 0.26$; $\kappa = 0.12$). It was decided to drop these questions from the overall questionnaire.

### Evaluation of the questionnaire

The results from the evaluation and from the earlier testing are presented in Table 1. The level of agreement improved across the majority of questions, with the overall quality rating increasing from 0.44 (95% CI 0.41–0.46) to 0.61 (95% CI 0.60–0.62). Eighteen of the 20 questions achieved an acceptable level of reliability, one of the questions falling below the threshold of 0.4 was dependent on the previous criteria (clear aims) being fulfilled, and the other (information about local services) was not always applicable. The final questionnaire and handbook will be available online at www.discern-genetics.org.

## Discussion

The DISCERN-Genetics criteria provide the first standardised method to assess the quality of information for the public on genetic screening and testing. The criteria were developed from information covering a spectrum of genetic screening and testing situations to facilitate application to a wide range of conditions and settings, and were empirically tested by lay people, producers, and providers of health information. Genetic tests are available for all of the genetic conditions selected. For some of the conditions, such as haemochromatosis and cystic fibrosis, the tests are part of standard clinical practice, for others current policy and provision are being debated. A key concern with all of the conditions is the level of public knowledge in this rapidly evolving field.

We used qualitative methods to obtain the views of a wide range of users of information on genetic screening and testing, and quantitatively tested the reliability of the criteria. By including the views of users of genetic services, we were able to identify and address the complex issues faced by those considering whether to consent to a genetic test, and include aspects of evidence valued by end users. These included concerns about discrimination and privacy, how risks and benefits should be expressed, and variability in test performance. The initial lack of agreement on the wording for the risk criterion reflected variation in the interpretation of risk information, which is consistent with previous research.[6,26] Discussions explored the concepts behind a summary estimate of risk, and increased risk. Once these criteria have been made public, comparisons between different users of information on genetic screening and testing should be made.

The results of the quantitative analysis provided empirical evidence to guide discussion about which criteria should be dropped or changed. Testing for agreement between raters demonstrated that initially some of the criteria were not interpreted in the same way, and changes to the wording were required to remove ambiguity and improve the level of agreement. This is not unusual when measurements rely on some subjective assessment, hence the need for formal testing to avoid confusion and misinformed decision making. Even with concepts that are readily endorsed, such as the nature of the test or layout and design, the meaning of the concept can differ between users.[27] This will not only affect the appraisal of information but also the content included in production. Interestingly, the appraisers strongly advocated the inclusion of criteria related to the presentation of information, and despite changes to the wording and format of these criteria, the level of agreement remained poor.

We were surprised, given the investment in genetic research, by the low volume of detailed information available to the public on genetic screening and testing. We searched multiple sources of information on genetic testing and found few articles on the wide range of selected topics, even in settings where some tests are compulsory. This confirms the findings of a recent UK survey reporting that information on newborn bloodspot screening is incomplete and biased,[28] elsewhere it has been observed that information is nonexistent.[29] Without a sound knowledge base, informed decisions are impossible, particularly in the context of unknown risks and benefits. Recommendations on how to develop information to help informed decision making in the area of population-based research involving genetics have been widely discussed, [5,30] but do not address the range of information needs outside a research setting. DISCERN-Genetics will provide a mechanism for the assessment of high-quality information in this complex area by ensuring that patients and their families receive information about a genetic test in a consistent manner, irrespective of who is providing the information. The application of the criteria to existing information, with support from online training (www.discern-genetics.org), will help users readily identify gaps in information provision.

### Acknowledgements

*We thank the The Wellcome Trust for funding the study.*

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## Appendix A. DISCERN-Genetics Quality Criteria (this will be available on discern-genetics.org.uk at the time of publication)

### The rating scale

Each question is rated on a five-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.

| **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 carrier[1] and having the condition
- a description of the predicted course of the condition
- details of any complications

[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.**

| **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 mastectomy[2], termination of pregnancy

| **5. Is risk explained in simple terms?** | | | | |
|---|---|---|---|---|
| No | | Partially | | Yes |
| 1 | 2 | 3 | 4 | 5 |

Hint: Does the information explain the risk of developing, carrying or passing on the condition. Look for

- a reason as to why the reader might be at specific risk
- a description of the risk of having the faulty gene[3] compared with the risk of not having the faulty gene
- an explanation of the chance that the condition will not develop
- a comparison of the risk of developing the condition with the risk of getting other diseases or of other events occurring
- an explanation of risk in alternative formats e.g. 1 in 2 or 50%

| **6. Is the nature of the test clear?** | | | | |
|---|---|---|---|---|
| No | | Partially | | Yes |
| 1 | 2 | 3 | 4 | 5 |

Hint: Look for an explanation on the type of tests available or being offered. Is the test being done:

- to confirm a diagnosis where symptoms already exist (diagnostic test)

[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.**

[3]**If a gene is altered it may not work properly, and this can lead to a disease or condition. Such a (faulty) gene is referred to as a mutation.**

- to predict whether someone with a family history of a condition will develop the condition (presymptomatic test[4] e.g. Huntington's disease) or is likely to develop the condition (predictive test[5] e.g. familial breast cancer)
- to check whether someone is a carrier for a recessive disorder[6] (screening test)
- to screen for genetic disorders during pregnancy (i.e. a test of the fetus)
- to screen for genetic disorders in the newborn

| **7. Is the testing procedure described?** | | | | |
|---|---|---|---|---|
| No | | Partially | | Yes |
| 1 | 2 | 3 | 4 | 5 |

Hint: Look for an explanation on

- how the test is performed
- where you go to have the test
- if it hurts when you have the test
- the safety/risk of the procedure
- the waiting time for results
- whether the test is a standard test, part of a research programme, or if you have to pay for the test

| **8. Does the information describe how accurate the test results are?** | | | | |
|---|---|---|---|---|
| No | | Partially | | Yes |
| 1 | 2 | 3 | 4 | 5 |

Hint: look for areas of uncertainty in testing, for example

- an explanation as to how tests fail e.g. human error and laboratory error

Look for

- a description of the meaning of false negative[7] and false positive[8] test results

[4]A test in children or adults for disorders that do not produce symptoms of the condition until the individual affected has reached maturity or later adult life.
[5]A genetic test that provides information in the form of a predictive diagnosis – i.e. the possibility or likelihood that the disease in question will develop. These tests can be carried out at the pre-natal stage, during childhood or on adults.
[6]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.
[7]The result of the test is negative, but this is an error and the real result is positive.
[8]The result of the test is positive, but this is an error and the real result is negative.

- any evidence of local variations in laboratory results
- an explanation that a repeat test may be needed, and why
- an acknowledgement of any limitations of testing

| **9. Does the information explain what happens after the test?** | | | | |
|---|---|---|---|---|
| No | | Partially | | Yes |
| 1 | 2 | 3 | 4 | 5 |

Hint: Look for

- an explanation of follow up procedures
- a description of who gives the results
- a description of how the results are received

| **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 paternity[9] may be discovered

| 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 |

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

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 |