

**IMPROVING THE QUALITY OF THE WRITTEN
INFORMATION SENT TO WOMEN ABOUT
CERVICAL SCREENING**

Guidelines on the Content of Letters and Leaflets

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PREFACE

These guidelines are an update of the guidance published by the NHS Cervical Screening Programme (NHSCSP) in 1997 as *Improving the Quality of the Written Information Sent to Women about Cervical Screening: Guidelines on the Presentation and Content of Letters and Leaflets* (NHSCSP Publication No 5).¹ They are based on a systematic review undertaken by staff at the Cancer Research UK Primary Care Education Research Group. They summarise current NHSCSP guidance about sending written information to women about cervical screening, and the information that the research evidence suggests should be included in letters and leaflets.

The detailed criteria, supporting evidence with references and the evaluation are published as a separate document, *Improving the Quality of the Written Information Sent to Women about Cervical Screening: Evidence-based Criteria for the Content of Letters and Leaflets* (NHSCSP Publication No 26).²

The research project for the revision of these guidelines was supported by the NHS Cervical Screening Programme and Cancer Research UK. The authors and the NHSCSP would like to give special thanks to all those who generously provided them with unpublished work and grey literature. Particular thanks are due to Cancer Research UK colleagues for their advice and guidance.

1. GUIDANCE ON SENDING LETTERS AND LEAFLETS

Current NHSCSP guidance on sending written information to women about the cervical screening programme is summarised below.

- Women should be informed that having cervical screening at the recommended interval provides a low risk status rather than a no risk status of developing cervical cancer.
- A copy of the NHSCSP leaflet *Cervical Screening – The Facts* must be sent with all screening invitation letters.
- All women who have a cervical screening test should receive their test results in writing. It is the responsibility of the GP or other clinician requesting the cytology screening test to ensure that there is a system in place (this may be the routine call and recall system administered by primary care organisations).
- All women who have a cervical screening test should be told when they should expect to receive their test results. More than 80% of women who have a cervical screening test should receive their test result within four weeks of the date of the screening test, and 100% of women should receive their test result within six weeks of the date of the screening test*.
- A copy of the NHSCSP leaflet *What Your Abnormal Result Means* should be sent with all abnormal result letters.
- It is not appropriate to use a standard result letter to notify a woman of a test result that has a recommendation of urgent referral for colposcopy. A woman with a test result of severe dyskaryosis ?invasive or ?glandular neoplasia should be given her result on a personal basis in a manner that is appropriate for her individual circumstances.
- All women referred for colposcopy should receive a personalised letter of invitation and an information leaflet before their first colposcopy visit.
- A copy of the NHSCSP leaflet *The Colposcopy Examination* should be sent with all colposcopy invitation letters.

*These standards are being reviewed as part of the Government's commitment to speeding up the cervical screening programme.

2. REPORT RECOMMENDATION SYSTEM FOR CONTENT OF WRITTEN INFORMATION

The standards for the production of evidence-based guidelines have become increasingly rigorous since the publication of the 1997 NHSCSP report.¹ In the original publication, a recommendation system was adopted that incorporated two distinct levels: definite and suggestive. In the updated guidelines,² a separate recommendation system with three levels (screening standard, new definite and suggestive) has been adopted. The three levels are described in more detail in Table 1. The definite and suggestive categories cannot be compared between the two versions of the guidelines because they are based on different criteria.

Outcomes in the ‘main issues’ sections of the original report for which no new evidence was obtained during the current review process were designated as ‘screening standard’ or ‘suggestive’ depending on the recommendation level set by the 1997 NHSCSP report.¹

A ‘new definite’ recommendation was assigned to individual outcomes in which a body of quantitative and/or qualitative research evidence was graded as ‘high’ and/or ‘moderate’.

A ‘suggestive’ recommendation was assigned to individual outcomes in which a body of quantitative and qualitative research evidence was graded as ‘low’ and/or ‘very low’.

If an outcome was given a ‘suggestive’ recommendation by the original report and the new research evidence was graded as ‘high’ and/or ‘moderate’, the recommendation level in the updated guidelines was changed to ‘new definite’.

If an outcome was given as a ‘definite’ recommendation by the 1997 NHSCSP report¹ and the new research evidence was graded as ‘low’ and/or ‘very low’, the references from the original report were retrieved and assessed. The recommendation level was downgraded to ‘suggestive’ only if the research evidence base in the 1997 NHSCSP report¹ was determined to be weak.

All outcomes included in the ‘optional issues’ sections of the original report were designated as ‘suggestive’ and incorporated into the ‘main issues’ sections of the updated guidelines. If new research evidence relevant to a particular outcome in one of these sections was graded as ‘high’ and/or ‘moderate’, the recommendation level in the updated guidelines was changed to ‘new definite’. If new research evidence relevant to a particular outcome in one of these sections was graded as ‘low’ and/or ‘very low’, the recommendation level remained as ‘suggestive’.

Guidelines on the Content of Letters and Leaflets

Table 1 Description of report recommendation system

Recommendation	Recommendation definition
Screening standard (definite recommendations from 1997 report)	Existing definite (D) recommendation set by the NHSCSP in the 1997 report for which no new evidence was available for evaluation OR New quantitative and/or qualitative research evidence was available and graded as high and/or moderate
New definite (D)	New definite (D) recommendation where available quantitative and/or qualitative research evidence was graded as high and/or moderate
Suggestive (S)	Existing suggestive (S) or optional recommendation set by the NHSCSP in the 1997 report for which no new evidence was available for evaluation OR New quantitative and qualitative research evidence was available and graded as low and/or very low New suggestive (S) recommendation where available quantitative and qualitative research evidence was graded as low and/or very low

3. RECOMMENDATIONS FOR CONTENT OF LETTERS

3.1 Existing letters

The existing letters used by the NHSCSP are based on the guidance published in NHSCSP Publication No 5 and have been approved by the Advisory Committee on Cervical Screening.¹ Since this guidance was published, very little research evidence has been produced that specifically addresses questions relating to the content of NHSCSP letters and the information needs of women receiving these materials.

There is some evidence that both the provision of fixed appointments and the GP as signatory to the letters encourages acceptance of the screening invitation. Primary care trusts (PCTs) should consider using either or both of these strategies.

Abnormal result letters should include the medical term for the observed condition (eg dyskaryosis or cervical intraepithelial neoplasia), regardless of the letter's signatory. This enables women to seek appropriate further information from appropriate sources.

All comments regarding language terms and abbreviations that should be avoided or used with caution, as detailed in the leaflet section of the guidance, should be incorporated into all screening programme materials.

It is important to ensure that abnormal result letters are not sent so that they arrive at a weekend or on a Friday, when many women may have difficulty contacting their care providers.

3.2 Letter templates

The NHSCSP should continue to use the existing letter templates. Care should be taken to ensure that the language used in letters for patients is consistent with that recommended for the leaflets. Additional locally relevant information may include contact details for obtaining information in alternative formats, such as audio versions or Braille, or in other languages. General guidance on producing text is given in Appendix 1.

3.3 Recommendations

The summaries of recommendations for the content of letters are shown in the following tables:

Table 2	Invitation letter
Table 3	Normal result letter
Table 4	Inadequate result letter
Table 5	Borderline/mild dyskaryosis result letter
Table 6	Moderate dyskaryosis or worse result letter
Table 7	Colposcopy letter
Table 8	Treatment letter

Guidelines on the Content of Letters and Leaflets

Table 2 Invitation letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Screening interval	
1.1 Mention the screening interval	Screening standard
2. Eligible population	
2.1 Mention who the test is for	Screening standard
2.2 Refer to 'all' women	Screening standard
2.3 Mention the age group	Screening standard
3. Purpose of the test	
3.1 Explain the purpose of the test	Screening standard
3.2 Mention the detection of early cell changes; avoid using the term 'pre-cancer'	Screening standard
3.3 Exclude that the purpose of the test is to detect cancer	Screening standard
4. Validity of the test	
4.1 Mention the validity of the test	Screening standard
5. Further tests	
5.1 Explain the possible reasons for further tests	Suggestive
5.2 Mention the likelihood of being asked to return for further tests	Suggestive
5.3 Mention that the vast majority of conditions found can be treated; avoid using the term 'cure'	Suggestive
6. Appointment information	
6.1 Provide appointment information	Screening standard
6.2 Explain how to make an appointment	Screening standard
6.3 Explain how to change an appointment	Suggestive
6.4 Provide flexible appointment times, ie after hours: may want to consider providing a fixed appointment time	Screening standard Suggestive
6.5 Mention that the test is free and confidential	Suggestive
7. Choice of venue	
7.1 List options in the letter or on a separate sheet	Screening standard
8. Sample taker	
8.1 Mention who takes the sample	Screening standard
8.2 Mention if the woman's GP takes the sample	Screening standard
8.3 Mention the availability of a female sample taker	Screening standard
9. Test procedure	
9.1 Explain what the test involves	Suggestive
9.2 Describe the location of the cervix	Suggestive
9.3 Mention how long the test will take	Suggestive
9.4 Describe how the test will feel	Suggestive
10. Test results	
10.1 Explain how to obtain the result	Screening standard
10.2 Mention approximate waiting time	Screening standard
10.3 Explain the meanings of inadequate, normal and abnormal results	Suggestive
10.4 Mention that the majority of screening samples are normal	Suggestive
11. Invitation leaflet	
11.1 Mention the inclusion of a general cervical screening leaflet	Screening standard
12. Further information	
12.1 Explain where the woman can obtain further information: provide a name/ telephone number and provide names of organisations/books	Screening standard

Guidelines on the Content of Letters and Leaflets

Table 2 Continued

Main issues	
Outcomes	Overall recommendations
13. Effective call/recall system maintenance	
13.1 Mention that the woman should notify any change of address	Suggestive
13.2 Mention that the woman should notify if a screening sample has already been taken	Suggestive
14. Signatory	
14.1 Advantageous if the woman's GP signs the letter	Suggestive

Guidelines on the Content of Letters and Leaflets

Table 3 Normal result letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Test results	
1.1 Explain the meaning of the result	Screening standard
1.2 Use the word 'normal' instead of 'negative'	Screening standard
1.3 Mention that a normal result means low risk rather than no risk of developing cervical cancer	Suggestive
2. Recall policy	
2.1 Mention when the next screening test is due	Suggestive
2.2 Mention that the woman will be informed by letter	Suggestive
3. Further information	
3.1 Mention the possibility of an appointment with the woman's GP Explain where the woman can obtain further information: provide a name/telephone number and provide names of organisations/books	Screening standard
4. Unusual symptoms	
4.1 Mention that if the woman has any unusual bleeding or pain before her next screening test that she should contact her GP	Suggestive
5. Effective call/recall system maintenance	
5.1 Mention that the woman should notify any change of address	Suggestive

Guidelines on the Content of Letters and Leaflets

Table 4 Inadequate result letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Test results	
1.1 Explain the meaning of the result	Screening standard
1.2 Mention the term used (inadequate)	Screening standard
1.3 Mention how common it is to have an inadequate screening result	Screening standard
1.4 Give reasons for an inadequate screening result	Suggestive
1.5 Exclude statements intended to reassure, eg 'not to worry', 'nothing to worry about' or 'no big deal'	Suggestive
1.6 Exclude that repeat screening is necessary because of an 'unclear' result	Screening standard
2. Follow up	
2.1 Explain the importance of follow up	Suggestive
3. Appointment information	
3.1 Explain how to make an appointment	Screening standard
3.2 Explain how to change an appointment	Suggestive
3.3 Provide flexible appointment times, ie after hours	Screening standard
3.4 Mention not to make an appointment during a period	Suggestive
4. Choice of venue	
4.1 List options in the letter or on a separate sheet	Suggestive
5. Test results	
5.1 Explain how to obtain the result	Screening standard
5.2 Mention approximate waiting time	Suggestive
6. Further information	
6.1 Mention the possibility of an appointment with the woman's GP Explain where the woman can obtain further information; provide a name/telephone number and provide names of organisations/books	Screening standard
7. Effective call/recall system maintenance	
7.1 Mention that the woman should notify any change of address	Suggestive
7.2 Mention that the woman should notify if a repeat screening sample has already been taken	Suggestive

Guidelines on the Content of Letters and Leaflets

Table 5 Borderline/mild dyskaryosis result letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Meaning of the result	
1.1 Explain the meaning of the result	Screening standard
1.2 Mention the name of the condition	Screening standard
1.3 Mention how common it is to have an abnormal screening result	Screening standard
1.4 Mention that repeat screening is necessary to give the cervix a chance to return to normal	Screening standard
1.5 Exclude statements intended to reassure, eg 'not to worry', 'nothing to worry about' or 'no big deal'	Suggestive
1.6 Exclude that further investigation is due to infection/inflammation	Suggestive
2. Outcome of the abnormality	
2.1 Mention that the woman is unlikely to have cancer	Screening standard
2.2 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Suggestive
3. Follow up	
3.1 Explain the importance of follow up because of the possibility of progression of the condition	Screening standard
4. Appointment information	
4.1 Provide appointment information	Screening standard
4.2 Explain how to make an appointment	Screening standard
4.3 Explain how to change an appointment	Suggestive
4.4 Provide flexible appointment times, ie after hours	Screening standard
4.5 Mention that a reminder letter will be sent closer to the time	Suggestive
5. Test results	
5.1 Explain how to obtain the result	Screening standard
5.2 Mention approximate waiting time	Suggestive
6. Abnormal result leaflet	
6.1 Mention the inclusion of a result leaflet	Screening standard
7. Further information	
7.1 Mention the possibility of an appointment with the woman's GP. Explain where the woman can obtain further information; provide a name/telephone number and provide names of organisations/books	Screening standard
8. Effective call/recall system maintenance	
8.1 Mention that the woman should notify any change of address	Suggestive
8.2 Mention that the woman should notify if a screening sample has already been taken	Suggestive

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Table 6 Moderate dyskaryosis or worse result letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Meaning of the result	
1.1 Explain the meaning of the result	Screening standard
1.2 Mention the name of the condition	Screening standard
1.3 Mention how common it is to have an abnormal screening result	Screening standard
1.4 Exclude statements intended to reassure, eg 'not to worry', 'nothing to worry about' or 'no big deal'	Suggestive
1.5 Exclude that further investigation is due to infection/inflammation	Suggestive
1.6 Exclude that the woman does not have cancer	Suggestive
2. Outcome of the abnormality	
2.1 Mention that the woman is unlikely to have cancer	Screening standard
2.2 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Screening standard
3. Further investigation	
3.1 Explain the nature of further investigation	Screening standard
3.2 Mention that treatment is effective	Suggestive
3.3 Mention that treatment can be carried out as an outpatient procedure	Screening standard
3.4 Mention that treatment should not affect the woman's reproductive or sexual function	Suggestive
3.5 Give advice about sex after receipt of an abnormal screening result	Suggestive
4. Follow up	
4.1 Explain the importance of follow up because of the possibility of progression of the condition	Screening standard
5. Appointment information	
5.1 Provide appointment information	Screening standard
5.2 Explain how to make an appointment	Screening standard
5.3 Explain how to change an appointment	Suggestive
5.4 Mention approximate waiting time for further investigation	Screening standard
6. Abnormal result leaflet	
6.1 Mention the inclusion of a result leaflet	Screening standard
7. Further information	
7.1 Mention the possibility of an appointment with the woman's GP	Screening standard
Explain where the woman can obtain further information; provide a name/telephone number and provide names of organisations/books	

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Table 7 Colposcopy letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Explain why colposcopy is needed	
1.1 Explain the meaning of an abnormal screening result	Screening standard
2. Appointment information	
2.1 Provide specific appointment information (time, date)	Suggestive
2.2 Explain where to go for the examination; provide a map	Suggestive
2.3 Explain how to change the appointment	Suggestive
3. Colposcopy visit	
3.1 Explain the examination; explain the function of a colposcope	Screening standard
3.2 Mention how long the examination will take	Suggestive
3.3 Mention when the results will be available	Screening standard
4. Colposcopy leaflet	
4.1 Mention the inclusion of a colposcopy/treatment leaflet	Screening standard
5. Further information	
5.1 Explain where the woman can obtain further information; provide a name/telephone number for the clinic and provide names of organisations/books	Screening standard

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Table 8 Treatment letter: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Explain why treatment is needed	
1.1 Explain what the condition is	Screening standard
2. Appointment information	
2.1 Provide specific appointment information (time, date)	Suggestive
2.2 Mention if the treatment is an inpatient or outpatient procedure	Screening standard
2.3 Explain where to go for the examination; provide a map	Screening standard
3. Explain the treatment visit	
3.1 Explain the procedure	Screening standard
3.2 Give preparation information	Suggestive
3.3 Mention how long the procedure will take (outpatient)	Suggestive
3.4 Mention how long hospitalisation will take (inpatient)	Suggestive
4. Treatment outcome	
4.1 Explain the outcome of treatment	Screening standard
4.2 Mention that treatment is effective	Screening standard
4.3 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Screening standard
4.4 Mention that the woman is unlikely to have cancer	Screening standard
5. Follow up	
5.1 Explain the follow up procedure. Mention how many follow up visits are needed and what happens at these follow up visits	Screening standard
6. Treatment leaflet	
6.1 Mention the inclusion of a treatment leaflet	Screening standard
7. Further information	
7.1 Explain where the woman can obtain further information; provide a name/telephone number for the clinic and provide names of organisations/books	Screening standard

4. RECOMMENDATIONS FOR CONTENT OF LEAFLETS

4.1 National leaflets

To help women make suitable decisions about whether or not to attend for screening, and to ensure that women receive appropriate information at each step of the screening process, the NHSCSP will continue to produce regularly reviewed and updated leaflets that incorporate the concepts presented in the full summary recommendation tables given in this document.

Copies of national leaflets are available to order from the Department of Health Publications Orderline: dh@prolog.uk.com (Tel.08701 555 455). PDF versions can also be downloaded from the NHS Cancer Screening Programme website at www.cancerscreening.nhs.uk.

Foreign language PDF versions of the leaflets in plain text A4 format are also available to download from the website (currently in 18 languages plus English).

4.2 Invitation leaflet

Items that should be included in the invitation leaflet are:

- Nature and purpose of the test.
- Validity of the test (including information on false positive and false negative results).
- Eligible population and screening interval.
- Test procedure.
- Test results (including the meaning of inadequate, normal and abnormal results).
- Causes of an abnormal result.
- Further tests.

The possible reasons for further tests and the likelihood of being asked to return for another test should be given in the invitation leaflet. However, detailed information about colposcopy and subsequent treatment should not be given until later in the screening process. The amount of information provided about further tests and investigations and the effectiveness of treatment and follow up should increase as a woman progresses from the abnormal result stage to colposcopy and treatment.

Guidelines on the Content of Letters and Leaflets

Table 9 Invitation leaflet: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Nature of the test	
1.1 Explain the preventative nature of the test	Screening standard
1.2 Exclude the timescale for cervical cancer to develop	Screening standard
2. Purpose of the test	
2.1 Explain the purpose of the test	Screening standard
2.2 Mention the detection of early cell changes; avoid using the term 'pre-cancer'	Screening standard
2.3 Exclude that the purpose of the test is to detect cancer	Screening standard
3. Validity of the test	
3.1 Mention the validity of the test	Screening standard
4. Eligible population	
4.1 Mention who the test is for	Screening standard
4.2 Refer to 'all' women	Screening standard
4.3 Mention the age group	Screening standard
4.4 Mention that the test is for women who have ever had sex	Screening standard
4.5 Mention specific issues for older and younger women	Suggestive
4.6 Mention that the cervical screening test is still applicable for menopausal women	Suggestive
5. Screening interval	
5.1 Mention the screening interval	Screening standard
5.2 Mention why the specified interval is used	Screening standard
6. Test procedure	
6.1 Explain what the test involves	Screening standard
6.2 Describe the location of the cervix	Screening standard
6.3 Mention how long the test will take	Screening standard
6.4 Describe how the test will feel	Screening standard
6.5 Explain what the speculum is	Screening standard
6.6 Mention not to make an appointment during a period	Suggestive
6.7 Mention to avoid using spermicides before having a screening sample	Suggestive
6.8 Mention that a full skirt is appropriate to wear	Suggestive
7. Choice of venue	
7.1 List options in the leaflet or on a separate sheet	Screening standard
8. Sample taker	
8.1 Mention who takes the sample	Screening standard
8.2 Mention if the woman's GP takes the sample	Screening standard
8.3 Mention the availability of a female sample taker	Screening standard
9. Test results	
9.1 Explain how to obtain the result	Screening standard
9.2 Mention approximate waiting time	Screening standard
9.3 Explain the meaning of inadequate, normal and abnormal results	Suggestive
9.4 Mention that the majority of screening samples are normal	Suggestive
10. Further tests	
10.1 Explain the possible reasons for further tests	Suggestive
10.2 Mention the likelihood of being asked to return for further tests	Suggestive
10.3 Explain the cause(s) of an abnormal screening result	Suggestive
10.4 Mention that the vast majority of conditions found can be treated; avoid using the term 'cure'	Suggestive
10.5 Exclude any information about colposcopy and treatment	Screening standard

Table 9 Continued

Main issues	
Outcomes	Overall recommendations
11. Preventative information	
11.1 Give preventative information	Suggestive
11.2 Explain the role of smoking	Suggestive
11.3 Explain the role of condoms	Suggestive
12. Further information	
12.1 Explain where the woman can get further information; provide a name/telephone number and provide names of organisations/books	Screening standard

Notes to Table 9

Recommendation 2: Purpose of the test

2.2 Mention the detection of early cell changes

- Evidence collected from women that have received an abnormal screening result indicates that the term ‘pre-cancer’ is not well understood and should be avoided.

Recommendation 9: Test results

9.3 Explain the meaning of inadequate, normal and abnormal results

- It is important to convey that a normal result means ‘low risk rather than no risk’ of developing future cervical abnormalities.
- Women’s understanding of cervical screening test results is improved when simpler statements are used rather than more complicated descriptions.

Recommendation 10: Further tests

10.3 Explain the cause(s) of an abnormal screening sample

- Further information about HPV infection was requested by women taking part in several studies.
- When describing HPV infection, the term ‘wart virus’ should be avoided.

10.4 Mention that the vast majority of conditions found can be treated

- Evidence collected from women who have received an abnormal screening result indicates that the term ‘cure’ creates confusion and should be avoided.

4.3 Abnormal result leaflet

Items that should be included in the abnormal result leaflet are:

- Meaning and causes of an abnormal result (describe the frequency of follow up).
- Abnormal result outcomes (ie women are unlikely to have cancer).
- Further tests and investigations (explain what colposcopy involves).
- Effectiveness of treatment.
- Importance of attending follow up.
- Sexual advice.

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Table 10 Abnormal result leaflet: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Meaning of the result	
1.1 Explain the meaning of the result	Screening standard
1.2 Exclude the term 'pre-cancer'	New definite
1.3 Exclude generic non-specific terms, eg 'mild cellular changes' or 'certain changes'	New definite
1.4 Exclude statements intended to reassure, eg 'not to worry', 'nothing to worry about' or 'no big deal'	New definite
1.5 Mention the name of the condition	Screening standard
1.6 Use the word 'normal' instead of 'negative'	Screening standard
1.7 Mention how common it is to have inadequate, normal or abnormal screening results	Screening standard
1.8 Mention if repeat screening is required	Screening standard
1.9 Mention what action is required for abnormal and normal results	Suggestive
1.10 Mention that repeat screening is necessary to give the cervix a chance to return to normal	Screening standard
1.11 Give reasons for an inadequate screening sample	Suggestive
1.12 Exclude that further investigation is due to infection/inflammation	Suggestive
2. Cause(s) of an abnormal screening result	
2.1 Explain the cause(s) of an abnormal screening result	Screening standard
2.2 Exclude the term 'wart virus'	New definite
3. Outcome of the abnormality	
3.1 Mention that the woman is unlikely to have cancer	Screening standard
3.2 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Screening standard
4. Further investigation	
4.1 Explain the nature of further investigation	Screening standard
4.2 Explain what colposcopy involves	Screening standard
4.3 Describe how colposcopy feels	Screening standard
4.4 Mention that treatment is effective	Screening standard
4.5 Mention that treatment can be carried out as an outpatient procedure	Screening standard
5. Follow up	
5.1 Mention the importance of follow up because of the possibility of progression of the condition	Screening standard
6. Give sexual advice	
6.1 Mention that treatment should not affect the woman's reproductive or sexual function	Screening standard
6.2 Give advice about sex after receipt of an abnormal screening result	Screening standard
7. Preventative information	
7.1 Give preventative information; explain the roles of condoms, smoking and the importance of regular screening	Suggestive
8. Further information	
8.1 Explain where the woman can obtain further information; mention the possibility of a GP appointment; provide a telephone number and provide names of organisations/books	Screening standard

Notes to Table 10

Recommendation 1: Meaning of the result

1.1 Explain the meaning of the result

- The terms 'abnormal', 'slight abnormality' and 'atypical' should be avoided; if 'borderline' and 'abnormal' are used, these terms require careful explanation.

Recommendation 2: Cause(s) of an abnormal screening result

2.1 Explain the cause(s) of an abnormal screening result

- Further information about HPV infection was requested by women taking part in several studies.
- Information was also requested about the impact of smoking on an abnormal screening sample.

Recommendation 3: Outcome of the abnormality

3.2 Mention the likelihood of treatment being effective

- Evidence collected from women who have received an abnormal screening result indicates that the term 'cure' creates confusion and should be avoided.

Recommendation 4: Further investigation

4.1 Explain the nature of further investigation

- The technical term punch biopsy and the abbreviation LEEP (loop electrosurgical excision procedure) caused difficulties for women interpreting information about the nature of further investigation.

Recommendation 5: Follow up

5.1 Mention the importance of follow up due to the possibility of progression of the condition

- Women require a clear explanation about what follow up involves and the reasons for attending any future appointments.

4.4 Colposcopy leaflet

Items that should be included in the colposcopy leaflet are:

- Explanation of why colposcopy is needed.
- Description of the colposcopy visit (include practical information).
- Explanation of the outcomes of colposcopy examination (including the possibility that treatment may be performed at the first visit).
- Effectiveness of treatment.
- Follow up.
- Aftercare (including practical information such as details about bleeding/discharge and sexual advice).

Guidelines on the Content of Letters and Leaflets

Table 11 Colposcopy leaflet: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Explain why colposcopy is needed	
1.1 Explain the meaning of an abnormal screening result	Screening standard
1.2 Give a name for the condition on the screening sample (dyskaryosis)	Screening standard
1.3 Mention the possibility of progression of the condition	Screening standard
1.4 Explain the cause(s) of an abnormal screening result	Screening standard
1.5 Mention how common it is to have an abnormal screening result	Screening standard
2. Colposcopy visit	
2.1 Mention that the woman can bring someone along to the clinic	Screening standard
2.2 Mention who will be present at the examination	New definite
2.3 Mention how long the examination will take	Suggestive
2.4 Mention that the woman should bring sanitary protection	New definite
2.5 Explain the examination	Screening standard
2.6 Mention what instruments are used, eg colposcope, stirrups, speculum	New definite
2.7 Mention that the colposcope does not go inside	Suggestive
2.8 Mention the possibility of a biopsy being taken	Screening standard
2.9 Provide advice for pregnant women	Suggestive
2.10 Mention what is felt during the examination	Suggestive
2.11 Mention if any pain is felt during the examination	Screening standard
2.12 Mention the possibility of local anaesthetic	New definite
2.13 Mention that the clinic staff are happy to answer questions	New definite
2.14 Mention what to wear	Suggestive
2.15 Give advice about menstruation and appointment date	Suggestive
2.16 Give advice about relaxation (breathing), distraction and/or other coping techniques	Suggestive
3. Explain the outcome of colposcopy examination	
3.1 Give a name for the diagnosed condition (CIN)	Screening standard
3.2 Mention the possibility of treatment at the first visit	New definite
3.3 Mention (local) treatment options	Screening standard
3.4 Mention that treatment is effective	Screening standard
3.5 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Screening standard
3.6 Mention that the woman is unlikely to have cancer	Screening standard
3.7 Explain the follow up procedure	Screening standard
4. Aftercare	
4.1 Give practical advice	Screening standard
4.2 Give advice about bleeding/discharge	New definite
4.3 Give advice about driving	New definite
4.4 Give advice about activity level after appointment	New definite
4.5 Give advice about sex after colposcopy	Suggestive
4.6 Exclude advice to a woman to change her form of contraception	New definite
4.7 Mention that examination should not affect future fertility/pregnancy	Screening standard
4.8 Explain if partner should be checked	Suggestive
4.9 Mention emotional upset	Suggestive
5. Further information	
5.1 Explain where the woman can get further information; provide a name/telephone number for the clinic and provide names of organisations/books	Screening standard

Notes to Table 11

Recommendation 1: Explain why colposcopy is needed

- 1.1 Explain the meaning of an abnormal screening result
 - Women have unanswered questions about their cervix and a diagram may be useful.
- 1.3 Mention the possibility of progression of the condition
 - Further details about follow up and the importance of regular cervical screening tests were requested by women newly referred for colposcopy after receiving an abnormal screening test result.
- 1.4 Explain the cause(s) of an abnormal screening result
 - Most women in several qualitative studies did not understand the specific meanings of terms such as ‘wart virus’ and ‘pre-cancer’; these terms should be avoided.
 - More information about HPV, including symptoms and treatment, was requested by women taking part in two studies.

Recommendation 2: Colposcopy visit

- 2.2 Mention who will be present at the examination
 - Women wanted to know whether their partner could come into the treatment room during the procedure and whether a nurse would be there to support them.
- 2.5 Explain the examination
 - The technical term punch biopsy and the abbreviation LEEP caused difficulties for women interpreting information about the colposcopy examination and treatment in one qualitative study.
- 2.11 Mention if any pain is felt during the examination
 - Women newly referred for colposcopy value the provision of information about pain that may be experienced during the examination; however, the details presented should not be too explicit, such as to indicate that the procedure is inherently painful.

Recommendation 3: Explain the outcome of the colposcopy examination

- 3.2 Mention the possibility of treatment at the first visit
 - The women participating in one qualitative study expressed frustrations about not receiving definitive treatment while a wait-and-see approach to care was followed.
- 3.5 Mention the likelihood of treatment being effective
 - Evidence collected from women who have received an abnormal screening result indicates that the term ‘cure’ creates confusion and should be avoided.
- 3.7 Explain the follow up procedure
 - A clear explanation of the number of follow up appointments required and the possibility of recurrence of abnormalities was requested by women in several studies.

4.5 Treatment leaflet

Items that should be included in the treatment leaflet are:

- Explanation of why treatment is needed.
- Description of the treatment visit (including practical information).
- Aftercare (including practical information and sexual advice).
- Explanation of the outcomes and effectiveness of treatment.
- Follow up.

Guidelines on the Content of Letters and Leaflets

Table 12 Treatment leaflet: summary of recommendations

Main issues	
Outcomes	Overall recommendations
1. Explain why treatment is needed	
1.1 Explain what the condition is	Screening standard
2. Explain the treatment visit	
2.1 Mention that the woman can bring someone along to the clinic (outpatient)	Screening standard
2.2 Mention who will be present at the treatment appointment	New definite
2.3 Explain the procedure	Screening standard
2.4 Mention sensations during the procedure, eg what is felt, seen, smelt and heard	Screening standard
2.5 Mention if any pain is felt during the examination	Screening standard
2.6 Mention the possibility of anaesthetic	New definite
2.7 Mention how long the procedure will take (outpatient)	New definite
2.8 Mention how long hospitalisation will take (inpatient)	Suggestive
3. Aftercare	
3.1 Give practical advice; mention recovery period, use of sanitary pads/tampons, bleeding/discharge after treatment, possible pain after treatment, use of painkillers and emotional upset	Screening standard
3.2 Give advice about sex after treatment	Screening standard
3.3 Mention that treatment should not affect future fertility/pregnancy	Screening standard
3.4 Give advice on future contraception	Screening standard
4. Treatment outcome	
4.1 Explain outcome of treatment	Screening standard
4.2 Mention that treatment is effective	Screening standard
4.3 Mention the likelihood of treatment being effective; avoid using the term 'cure'	Screening standard
4.4 Mention that the woman is unlikely to have cancer	Screening standard
5. Follow up	
5.1 Explain the follow up procedure; mention how many follow up visits are needed and what happens at these follow up visits	Screening standard
6. Further information	
6.1 Provide a name/telephone number for the clinic	Screening standard
6.2 Provide names of organisations/books	Screening standard

Notes to Table 12

Recommendation 1: Explain why treatment is needed

- 1.1 Explain what the condition is
- The term 'CIN' requires careful explanation.

Recommendation 2: Explain the treatment visit

- 2.3 Explain the procedure
- The technical term 'cold coagulator' and the abbreviation LLETZ (large loop excision of the transformation zone) caused difficulties for women interpreting information about the treatment procedure.
- 2.5 Mention if any pain is felt during the examination
- Women indicated that the information provided about pain during the treatment procedure should not be too explicit.

Recommendation 3: Aftercare

- 3.1 Give practical advice
- Few of the women participating in one qualitative study knew how to interpret symptoms after treatment or what to do about any symptoms that developed.

Recommendation 4: Treatment outcome

- 4.3 Mention the likelihood of treatment being effective
- Evidence collected from women who have received an abnormal screening result indicates that the term 'cure' creates confusion and should be avoided.

5. DISCUSSION

These recommendations bring together the research evidence regarding women's information needs and the content of written information materials provided to women about cervical screening at all stages of the screening process. A range of research evidence was examined during the course of the review, with the main research questions being answered best by both quantitative and qualitative study findings. After assessing various guideline standards, it was decided that the GRADE system offered the most sensible and adaptable method for both types of research.³ Integrating quantitative and qualitative research into the same guidelines presented a significant methodological challenge, and little has been published in the literature that addresses this problem from a practical point of view. The quantitative evidence included in the review received quite low overall evidence ratings. This may be explained generally by the study designs used, ie cross-sectional and descriptive studies, which are rated lower in the GRADE evidence hierarchy as opposed to methodological issues such as selection bias or unreliable outcome assessment. The lack of randomised trials in this field may result from ethical concerns.

Studies that examined the information requirements of specific groups, such as individuals with disabilities, older and adolescent women and individuals from particular cultural or linguistic backgrounds, were excluded because the mandate of the review was to produce guidelines for the development of English language templates for the general screening population. Information materials for women from different communities should be developed separately for each target group, using these recommendations as a basis. Studies that described interventions designed to increase screening uptake were not included in the review unless the content of the participant information materials used was evaluated and/or included with the study report. Research that provided evidence of knowledge, attitudes, health beliefs or barriers towards cervical screening was excluded from the review process unless women's information needs were discussed or written information materials were described. The design of the leaflets and letters has not been considered in this report because we expect that the guideline recommendations will be incorporated into current screening programme materials using existing, established designs.

Women attending for routine cervical screening expect to receive confirmation that they are healthy; a cervical screening test may even be viewed as a form of 'insurance policy' against cancer.⁴⁻⁶ Few women actually consider what an abnormal result might mean for them personally until the moment that such a result is received.^{4,5} Fear of cancer and worry about death are significant issues for women with abnormal results.⁷ Women are also troubled by the lack of a label for their condition. The first abnormal result notification neither indicates that a disease is present nor confirms a state of good health.^{5,8} In fact, both remain a possibility. Generally, women have a poor understanding of the inherent ambiguity associated with an abnormal screening result, and this uncertainty is an

important source of distress.^{5,8} Another aspect of the screening process that causes confusion is the follow up procedure. Women appreciate that it is important to attend for further tests, but become frustrated by the fact that follow up appointments are scheduled for many months ahead instead of immediately.^{4,8-11} As such, a clear explanation of the rationale behind a 'wait and see' approach would be helpful.

The NHSCSP is an established and accepted component of the healthcare system. However, the public is much less aware of, and knowledgeable about, human papillomavirus (HPV) infection. A recent study investigating beliefs about the risk factors for cervical cancer in a sample of the British population showed that knowledge of the role of HPV in cervical cancer aetiology was low; therefore, any information provided about the role of sexual transmission may be at odds with current beliefs.¹² If HPV testing is adopted for widespread use within the NHS, very clear information about all aspects of HPV infection must be given in the invitation materials.¹³ Because a large amount of information must be given in order to meet informed choice requirements, a separate leaflet dedicated to HPV education is likely to be required to address the many issues raised by the provision of HPV testing.¹²⁻¹⁴ In one qualitative study, women struggled to understand how HPV infection could resolve over time without intervention and expressed confusion about how cervical screening test results could be normal if HPV is present.¹⁵ The distinction between low risk and high risk forms of HPV is not well understood, particularly when any explanation is linked with the term 'wart', which for many women carries a significant stigma.^{15,16} The sexually transmitted nature of the virus, along with the present lack of knowledge about HPV itself and the sexual health of partners, means that the screening programme will be entering into a new and complex health education domain.^{16,17} Further information about the relationship between smoking and the progression from HPV infection to cancerous changes will also be required.¹³ Any new information materials will need to be developed with care so that participants in the screening programme do not acquire the wrong impression that the cervix, and not the woman, is the main focus and concern of the programme.^{4,18}

The clear communication of these concepts to women participating in the screening programme is a continuing challenge. A number of studies have indicated that women's understanding is improved when thorough yet simple information materials are provided.¹⁹⁻²² The addition of further explanatory sentences or the inclusion of detailed statistics have not yet been shown to improve understanding beyond that achieved with simple statements.^{20,21} None of the grey literature that was obtained during the course of the review provided further evidence to support the inclusion of statistical descriptions. This issue will be explored further in a series of focus groups with women at various stages of the cervical screening process.

Consistent terminology should be used in all screening materials, and unnecessary technical terms and abbreviations should be avoided. It has been suggested that the use of a light hearted tone is not helpful because it may give the impression that a serious health concern is being trivial-

ised.²³ Similarly, statements that intend to reassure, such as ‘it’s nothing’ or ‘not to worry’, should not be included because they do not match the woman’s perception that ‘something’ has been discovered by the cervical screening test.^{5,8,10,11} The term ‘cure’ should also be avoided because it does not help to clarify that dyskaryosis and CIN fall between normality and invasive disease, which leaves women feeling uncertain of exactly what they can be cured of by treatment.⁵

Informed choice is becoming increasingly important in screening.²⁴⁻²⁷ As such, it is vital that women understand both the aims and limitations of cervical screening.

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APPENDIX 1: GENERAL GUIDELINES ON PRODUCING TEXT

As stated previously, it is recommended that the letter templates produced by the NHSCSP be used. When formatting the text, the following should be considered:

- avoid small type (a minimum of 12 point is recommended)
- large print documents are generally produced in 16–22 point type
- use a clear legible typeface, such as Arial, Univers or New Century Schoolbook
- avoid using text that is all capital letters or italicised because this is harder to read
- print headings and important statements in bold to attract attention.

The NHSCSP produces leaflets that are intended to accompany an invitation letter, an abnormal results letter and a colposcopy appointment letter. For additional locally produced information, the following may be considered.

Writing

- Use introductions to state the purpose of the information to the reader.
- Summarise at the end of major topics in order to review key points.
- Use titles and subtitles to clearly define the flow of ideas.
- Use short and succinct sentences and paragraphs.
- Use pronouns such as ‘we’ and ‘you’ to personalise text.
- Write in the active, not passive, voice (A sees B, rather than B was seen by A).
- Clarify points with examples.
- Avoid polysyllabic words where possible.
- Use clear, simple language and informal expressions.
- Avoid jargon.
- Avoid abbreviations and acronyms.
- Avoid the use of double negatives.

Design (see also the points above on the formatting of text)

- Use bullets to reinforce points.
- Use ragged right hand margins instead of justified text to make it seem less formal.
- Use graphics to reinforce, not compete with, the text.
- Illustrations, photographs and graphics can make information more friendly.
- Use professional drawings.
- Avoid technical drawings.
- Use pastel or mid-range coloured shades, or restrict to two brighter colours.
- The better the contrast between background and text, the more legible the text.
- Do not print alarming words such as ‘cancer’ in bold.
- Large page numbers can distract from the text.
- Position page numbers on the right hand margin to allow people to flick through the text.
- Booklets produced in A5 format allow for clear text and graphics.
- Avoid unnecessary capital letters.