

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

**Guidelines on the Content of
Letters and Leaflets**

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**NHSBSP Publication No 65
August 2007**

Published by:

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ISBN 978-1-84463-045-5

Further copies of this publication are available from the Department of Health Publications Orderline quoting NHSBSP Publication No 65

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Typeset by Prepress Projects Ltd, Perth (www.prepress-projects.co.uk)

Printed by Charlesworth

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PREFACE

These guidelines are based on a systematic review undertaken by staff at the Cancer Research UK Primary Care Education Research Group. They summarise, in the form of practical checklists, current NHS Breast Screening Programme (NHSBSP) policies and standards for written information and the issues that the research evidence suggests should be included in the leaflets and letters. They update and replace Guidelines on Improving the Quality of the Written Information Sent to Women who are Recalled for Assessment (NHSBSP Publication No 38), which was published in 1998.

The detailed criteria and the supporting evidence are published as a separate document: Improving the Quality of the Written Information Sent to Women about Breast Screening: Evidence-based Criteria for the Content of Letters and Leaflets (NHSBSP Publication No 64).

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 The authors would like to give special thanks to all those who generously provided them with unpublished work and grey literature.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

FOREWORD

The NHS Breast Cancer Screening Programme has always prided itself on being both evidence-based and paying considerable attention to the psychological as well as physical care of the women it serves. From the outset, great care has been taken to minimise the anxiety inevitably provoked by breast screening and, in particular, attention has been paid to women recalled for assessment. In this, the NHSBSP has been well supported by the Cancer Research UK Primary Care Education Research Group in Oxford. Most recently, they have worked with the programme to produce the national Facts leaflet, which embraces the policy of informed choice and is sent to all women with their invitations.

These two organisations have now undertaken a complete review of the quality of written information sent to women and, here, they make recommendations based on this evidence. A companion volume (NHSBSP Publication No 64) contains the evidence itself.

These guidelines now require action. Some issues will be for local programmes to take up. In particular, the exact wording of letters is a local issue. The invitation leaflet is a national issue and, over the next 12 months, work will be carried out to review, redraft and test a new version of the Facts leaflet to bring it in line with changes in the programme and with the latest evidence. There is also an Understanding Breast Screening booklet sponsored by the NHSBSP with Cancerbackup. This is for women who want more information either at invitation or at recall. This will also be looked at in light of these new guidelines.

Keeping information materials up to date is as important to the NHSBSP as keeping up to date technically. These documents enable us to ensure that we are in step with the latest evidence.

Julietta Patnick CBE

Director, NHS Cancer Screening Programmes

22 March 2007

1. INTRODUCTION

1.1 Review aims

The aim of this review is to improve the quality of the content of letters and leaflets sent to women at all stages of the breast screening process. Previous evidence-based guidance was published in 1998 for the information materials associated with recall for assessment. However, no screening standards have been produced for the invitation materials. Two main questions were addressed:

- What is the existing research evidence base regarding the content of written information sent to women at all stages of the breast screening process?
- What are the information needs of women at all stages of the breast screening process?

The answers to these questions helped to guide the development of the recommendations for the content of all of the leaflets and letters to be used in the NHSBSP.

1.2 Methods

1.2.1 Data sources

Systematic searches of 13 electronic databases (between 1989 and August 2005) were conducted. Additional references were located by searching the table of contents of selected journals, the reference sections of relevant papers and Internet resources. Both published and unpublished studies were included.

1.2.2 Study selection

All studies that evaluated the content of information materials provided to women about breast screening or that addressed the information needs of women at all stages of the breast screening process were assessed for inclusion.

1.2.3 Data extraction

The data extraction form and quality assessment criteria were developed from published resources. Two reviewers independently assessed titles and abstracts of papers as well as full study reports. Data were extracted from relevant studies by one reviewer and checked by a second reviewer. Any uncertainty was resolved by discussion.

1.2.4 Data synthesis

A non-quantitative synthesis was conducted and a tabular evidence profile for each important outcome (eg 'Explain the need for breast compression') was prepared. Outcomes were drawn from research evidence, the 1998 NHSBSP recall information guidelines and expert opinion. The overall quality of evidence for each outcome was then assessed using an approach published by the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group that was adapted to suit the review questions and modified to include qualitative research evidence. Four key elements were considered in each evidence profile: study design, study quality, consistency and directness. Quantitative and qualitative studies as well as expert opinion were considered separately for every outcome.

1.3 Results

A total of 3536 citations were identified as potentially relevant by electronic database searches and other search strategies. After the titles and abstracts of the citations had been independently prescreened by two reviewers, 361 papers remained for possible inclusion. The full report of each of these papers was obtained and scanned for relevance – full data extraction was conducted for 100 of the papers. Following data extraction and assessment of methodological quality, a grand total of 31 papers were included in the systematic review.

Recommendations were included for the breast screening programme letters, although little research literature has been published that specifically addresses questions related to the content of screening letters and the information needs of women receiving these materials.

Summary recommendation tables were developed for the invitation and recall leaflets. The list of outcomes considered for the invitation leaflet was extensive and a number of papers – both quantitative and qualitative – as well as expert opinion were assessed. Research evidence was considered for almost every section of the invitation leaflet; however, there was limited evidence available for a number of the items of information. The quantitative evidence included in the review received quite low overall evidence ratings. This may generally be explained by the study designs used (ie non-comparative 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 content of the existing NHSBSP invitation leaflet was included in the summary tables to allow for comparison with current practice.

New research evidence was assessed for a majority of recall leaflet outcomes. Several new items of information were added to the outcomes recommended in the 1998 NHSBSP guidance. A selection of the changes incorporated include:

- mention technical errors
- present information about the future risk of developing breast cancer
- discuss benign conditions that may be seen on mammograms (clearly explain terms such as ‘calcium spots’, ‘calcium deposits’, ‘calcifications’ and ‘cysts’)
- provide information about false positive and false negative results
- indicate that follow up may be necessary.

The diagnosis of ductal carcinoma in situ (DCIS) presents important issues for the breast screening programme. The questions surrounding DCIS are complex – confusion exists regarding disease progression and there is no optimal treatment strategy. Also, a limited amount of research evidence exists regarding women’s information needs about DCIS.

The review process identified some evidence related to interventions designed to improve mammography uptake and maintain adherence. Evidence of improved uptake at invitation was seen with fixed appointments as opposed to open appointments, and there was some evidence

of improved uptake when a GP's signature was included on the screening programme invitation letter. Among screening non-attenders, a GP's endorsement of screening via a letter appeared to be effective and reminders were also found to be useful. The provision of additional educational information did not appear to improve uptake; however, general information may help to maintain mammography adherence. This topic has been covered in detail by a group of systematic reviews, and the search strategy used in this report was not designed specifically to address this issue.

1.4 Summary of recommendations

We recommend that the NHSBSP should continue to use the existing letter templates. However, consideration could be given to the content suggested by the European Communication Group and the evidence provided by the literature addressing interventions designed to improve mammography uptake and maintain adherence.

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 NHSBSP should endeavour to produce leaflets that incorporate the concepts presented in the full summary recommendation tables. At present, only an invitation leaflet is provided to women taking part in the programme (although further information about breast screening is available on request in the form of a Cancerbackup booklet). A nationally available recall leaflet (including information about DCIS) should be produced and distributed.

Examples of items that might be included in the invitation and recall leaflets are given below.

Invitation leaflet

- Screening programme information
- Nature and purpose of the test
- Breast cancer information
- Validity of the test (include information on false positive and false negative results)
- Benefits and risks of mammography
- Eligible population and screening interval
- Test procedure
- Test results (explain the meaning of the results)
- Further tests
- Treatment
- Preventative information.

The possible reasons for further tests and treatment should be described in the invitation leaflet. However, detailed information about further investigation and subsequent treatment should not be provided until later in the screening process. The amount of information provided about further tests and investigation, the effectiveness of treatment and follow up should increase as a woman progresses from abnormal result to further assessment and treatment.

Recall leaflet

- Meaning of an abnormal result (provide a clear reason for recall; include information on false positive and false negative results)
- Abnormal result outcomes (ie women are unlikely to have cancer)
- Provide appointment information
- Further tests and investigation (explain what further assessment involves)
- Follow-up
- Further information.

2. HOW TO PRESENT RISK INFORMATION

The presentation of risk information is problematic because the interpretation of risk language is not straightforward¹⁻⁶ and consensus is lacking on whether numerical data should be presented and in what form.^{2,5,7} Proponents of the inclusion of quantitative information about risks for disease believe that such information is an important component of informed decision making,^{3,5,8,9} whereas others suggest that the presentation of quantitative expressions may be confusing and meaningless.^{3-5,8} Several strategies for communicating risk information have been proposed,^{3,6,10} but the effectiveness of incorporating such approaches into screening programme materials is unknown. Messages constructed in both numeric and verbal formats may be advantageous because they benefit from the use of ordinary language as well as the precision of numbers.⁸

Although additional research work is required to determine which risk presentation options women prefer and find most useful, a set of key presentation points may be derived from the risk communication literature (Table 1). The key points summarised in Table 1 are largely based on theoretical work. It has been suggested that the risk information provided to women should be simple, balanced and relevant.^{4,11} This is supported by the findings of several studies in which no evidence of increased mammography uptake among women exposed to interventions incorporating additional educational information was shown.¹²⁻¹⁶ Inadequacies in literacy as well as numeracy must also be taken into account when developing risk information for inclusion in screening materials.^{2,3,8,17}

Table 1 Presenting risk information: key points^{3-6,9,18,19}

Present numerical probabilities as event rates (eg the number out of 100 women)
Use constant denominators rather than constant numerators (eg 4 out of 1000; 15 out of 1000)
Provide a meaningful timeframe over which events occur (10 years, lifetime)
Present event rates with visual aids (such as faces diagrams, bar charts and/or human figure representations)
Analogies may be useful for presenting small risks (eg one person in a concert hall crowd)
Provide the mortality benefit from screening as the probability of death with and without screening
Dual representations should be used (loss and gain, mortality and survival data) to counteract the influence of framing
Absolute risks should be given greater prominence than relative risks
If conditional probabilities are used, the baseline risk of the target condition should be provided
Put disease- or intervention-specific probabilities into context by comparing the risk with other common/uncommon events (eg winning the lottery, road crashes)
Acknowledge uncertainty in estimates by using phrases such as 'our best guess is ...', give ranges or provide 95% confidence intervals

3. REPORT RECOMMENDATION SYSTEM

3.1 Systems used

Two separate recommendation systems were developed for the screening information given out at invitation versus that at recall for further investigation.²⁰ Different systems were necessary as no evidence-based guidelines currently exist for the NHSBSP invitation materials, whereas guidance on improving the quality of the written information sent to women who are recalled for assessment was published in 1998.²¹ A recommendation system with four levels (definite, suggestive, expert opinion and current practice) was adopted for the invitation information, and a system with three levels (screening standard, definite and suggestive) was introduced for the information associated with recall.²⁰

3.2 Expert opinion

There is a lack of evidence-based guidance in the breast screening literature regarding the essential contents of patient information materials. During the course of the review, a number of expert opinion reports were identified that contained various recommendations for the content of breast screening materials as well as studies that used different checklists/questionnaires to evaluate both screening information and women's decision making about mammography. Often, little information was provided about the development of the checklists used in these studies – there was no indication of why particular items had been included. It was decided that the expert opinion reports and checklist type studies should be included in the review as a separate category of evidence distinct from the other quantitative and qualitative studies. This extra category was necessary to provide a complete picture of the existing evidence.

3.3 Report recommendation system: invitation information

The report recommendation system used for invitation information is shown in Table 2.

A 'Definite (D)' recommendation was assigned to individual outcomes with supporting quantitative and/or qualitative research evidence graded as 'high' and/or 'moderate'.

A 'Suggestive (S)' recommendation was assigned to individual outcomes with supporting quantitative and qualitative research evidence graded as 'low' and/or 'very low'.

An 'Expert opinion (E)' recommendation was assigned to individual outcomes with supporting quantitative and qualitative research evidence graded as 'low' and/or 'very low' and expert opinion support.

If no quantitative or qualitative research evidence relevant to a particular outcome was available for assessment but expert opinion supported inclusion, an 'Expert opinion (E)' recommendation was assigned.

All outcomes included in the existing NHSBSP invitation leaflet with no research evidence or expert opinion support were designated as 'Current practice'.

3.4 Report recommendation system: recall information	<p>The report recommendation system used for recall information is shown in Table 3.</p> <p>Key topics from the 1998 NHSBSP report²¹ for which no new evidence was obtained during the current review process were designated as ‘Screening standard’.</p> <p>A ‘Definite (D)’ recommendation was assigned to individual outcomes with supporting quantitative and/or qualitative research evidence graded as ‘high’ and/or ‘moderate’.</p> <p>A ‘Suggestive (S)’ recommendation was assigned to individual outcomes with supporting quantitative and qualitative research evidence graded as ‘low’ and/or ‘very low’.</p> <p>If the new research evidence for a key topic set by the 1998 NHSBSP report 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 evidence base in the 1998 NHSBSP report was determined to be weak.</p>
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Table 2 Description of report recommendation system: invitation information

Recommendation	Recommendation definition
Definite (D)	Definite (D) recommendation for which available quantitative and/or qualitative research evidence was graded as high and/or moderate
Suggestive (S)	Suggestive (S) recommendation for which available quantitative and qualitative research evidence was graded as low and/or very low
Expert opinion (E)	Expert opinion (E) recommendation for which available quantitative and qualitative research evidence was graded as low and/or very low and expert opinion reports supporting inclusion were available OR No quantitative or qualitative research evidence was available but expert opinion reports supporting inclusion were available
Current practice	Current practice recommendation for which an item of information is included in the existing NHSBSP invitation leaflet and no quantitative or qualitative research evidence or expert opinion reports were available

Table 3 Description of report recommendation system: recall information

Recommendation	Recommendation definition
Screening standard (key topics from the 1998 report)	Key topics set by the NHSBSP in the 1998 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
Definite (D)	Definite (D) recommendation for which available quantitative and/or qualitative research evidence was graded as high and/or moderate
Suggestive (S)	Suggestive (S) recommendation for which available quantitative and qualitative research evidence was graded as low and/or very low

4. RECOMMENDATIONS FOR THE CONTENT OF LETTERS

4.1 Letter content

All the existing invitation and results letters used by the NHSBSP have been approved by the Advisory Committee on Breast Screening, and those sent to women recalled for further assessment were developed according to guidance published in NHSBSP Publication No 38.²¹ Since the publication of the 1998 report, very little research evidence has been produced that specifically addresses questions related to the content of breast screening programme letters and the information needs of women receiving these materials. However, European guidelines have recently been published addressing the content of breast screening invitation materials,⁷ and a single focus group study of women taking part in the NHSBSP has assessed the wording of the results letter.²² A body of evidence related to interventions designed to improve mammography uptake and maintain adherence has also been considered.

4.2 Invitation letter

The European Communication Group's recommendations (developed by expert consensus) for the contents of breast screening invitation letters are summarised in Table 4.⁷ The guidance notes suggest that the invitation letter should be written in a simple, clear and readable style, and that the topics covered by the letter should be only briefly described because further relevant additional information may be included in an accompanying leaflet. It is also suggested that the letter should refer to the leaflet and that women should be encouraged to read it.⁷

4.3 Results letter

In one qualitative research project, 48 women with normal mammogram results who attended the Warwickshire, Solihull and Coventry Breast Screening Service were invited to attend a group discussion. Twenty-seven women screened at various sites attended a series of focus groups. Some women reported being dissatisfied with the wording of the results letter, especially the phrase 'No traces of cancer were found'. The women preferred the phrase 'negative result'.²²

Table 4 European Communication Group guidance on breast screening invitation letter content⁷

Invitation letter content

Purpose of screening
Who the test is for (target population – age group)
Mention the mammography test and its validity
Screening interval
Indicate whether the test is free or not
The appointment (how to make it, how to change it)
When and how to get the results (mention approximate waiting times)
Mention the possibility of being recalled for further tests
Other logistical information (eg clothing suggestions, deodorants)
Indicate where women can get further information
Data protection/confidentiality

4.4 Evidence from studies aimed at improving mammography uptake and maintaining adherence

This topic has been covered in detail by a group of systematic reviews.^{23–25} A number of studies reporting information based interventions aimed at improving mammography uptake and maintaining adherence are summarised in the accompanying evidence document.²⁰ Evidence of improved uptake at invitation was seen with fixed appointments as opposed to open appointments, and there was some evidence of improved uptake when a GP's signature was included on the screening programme invitation letter. Among screening non-attenders, a GP's endorsement of screening via a letter appeared to be effective, and reminders were also found to be useful. In general, additional educational information did not seem to improve uptake but the provision of general information could be helpful in maintaining mammography adherence.

4.5 Recommendations

We recommend that the NHSBSP should continue to use the existing letter templates but that modifications should be considered according to the research evidence described in this section. Also, care should be taken to ensure that the language used in the letters is consistent with that recommended for the leaflets. All comments regarding language terms and abbreviations to be avoided or used with caution as detailed in the leaflet section of this guidance should be incorporated into all NHSBSP materials. Finally, it is important to make certain that result letters are not sent so that they arrive on a weekend or a Friday, when many women may have difficulty contacting their care providers for further information.²¹

5. RECOMMENDATIONS FOR THE CONTENT OF LEAFLETS

Recommendations for the content of invitation leaflets are shown in Table 5.

Recommendations for recall leaflets are shown in Table 6.

Table 5 Invitation leaflet: summary of recommendations

Main issues		Overall recommendations
Outcomes		Expert opinion
Explain what the leaflet is for		
1. Screening programme information		
1.1	Explain what a screening programme is	Expert opinion
1.2	Mention how women are identified	Current practice
1.3	Mention that the woman should notify of any change of address	Current practice
1.4	Mention data confidentiality	Expert opinion
1.5	Mention quality control/operators' training	Expert opinion
2. Nature and purpose of the test		
2.1	Explain what a mammogram is	Expert opinion
2.2	Explain the purpose of mammography (early detection of cancer not prevention)	Expert opinion
3. Breast cancer information		
3.1	Provide the incidence of breast cancer	Definite
3.2	Give the mortality rates of breast cancer	Definite
3.3	State the lifetime risk of developing breast cancer	Definite
3.4	Give the 10 year risk of developing breast cancer	Suggestive
3.5	Mention the chance of developing breast cancer	Definite
3.6	State the lifetime risk of dying from breast cancer	Expert opinion
3.7	Provide the risk of dying from breast cancer	Expert opinion
3.8	Mention survival from breast cancer	Expert opinion
3.9	Describe the natural history of breast cancer	Suggestive
3.10	Describe breast cancer causes/risk factors	Definite
3.11	Mention possible effects of HRT	Suggestive
3.12	Mention the role of family history in breast cancer	Definite
3.13	Mention possible effects of menopause on mammography	Definite
4. Validity of the test		
4.1	Mention test accuracy (mention that some cancers are difficult to see; some cannot be seen; and some may be missed)	Definite
4.2	Give the proportion of breast cancers detected by mammography (sensitivity)	Expert opinion
4.3	Give the proportion of women without cancer who have a normal mammogram (specificity)	Expert opinion
4.4	State the proportion of women with positive mammograms who would have breast cancer (PPV)	Expert opinion
4.5	State the proportion of women with negative mammograms who would not have breast cancer (NPV)	Expert opinion
4.6	Provide information on the number of women needed to screen to avoid death from breast cancer	Definite

5. Why have the test		
5.1	State the relative risk reduction mortality	Expert opinion
5.2	Provide the absolute risk reduction mortality	Expert opinion
5.3	Give the risk reduction mortality (not otherwise specified)	Expert opinion
6. Benefits of mammography		
6.1	Provide mammography benefits	Definite
6.2	Mention the possibility of less invasive treatment	Expert opinion
7. Risks of mammography		
7.1	Mention detection of ductal carcinoma in situ (DCIS)	Definite
7.2	State the number of women diagnosed with DCIS annually	Definite
7.3	Mention the chance of 'pseudodisease' (ie DCIS or inconsequential disease)	Expert opinion
7.4	Mention radiation risks	Expert opinion
7.5	Provide an estimate of radiation risk	Definite
7.6	Mention discomfort/pain (eg how long compression lasts and possibility of persistent pain)	Definite
7.7	Explain the need for breast compression	Definite
7.8	Mention the possibility of recall	Expert opinion
7.9	Mention possible anxiety due to recall	Definite
7.10	Give the proportion of screened women who would be recalled	Expert opinion
7.11	Mention false positive results	Suggestive
7.12	Provide the proportion of women with false positive results	Expert opinion
7.13	Give the screening lifetime risk of false positive results	Expert opinion
7.14	Mention false negative results	Suggestive
7.15	Give the proportion of women with false negative results	Expert opinion
8. Eligible population		
8.1	Mention who the test is for	Expert opinion
8.2	Explain why asymptomatic women are involved	Expert opinion
8.3	Explain that women are invited on a practice by practice basis	Current practice
8.4	Mention the age group (explain that women will be called for the first time between the ages of 50 and 53 years)	Suggestive
8.5	Explain why women outside the age group are not invited for screening	Suggestive
8.6	Provide advice for women under 50 years who want to be screened	Suggestive
8.7	Provide advice for women over 70 years who want to be screened	Suggestive
9. Screening interval		
9.1	Mention the screening interval	Expert opinion
9.2	Mention why the specified interval is used	Suggestive
9.3	Mention increasing incidence with age/risk factor	Expert opinion
9.4	Mention increasing mortality with age	Expert opinion

Table 5 continued

Main issues	Overall recommendations
10. Appointment information	
10.1 Explain how to change an appointment	Expert opinion
10.2 Explain where to go for the test (eg mobile unit or static screening centre)	Definite
10.3 Explain how long an appointment lasts	Current practice
10.4 Provide advice about avoiding the use of talcum powder and spray deodorant before mammography	Suggestive
10.5 Mention if there are any documents women should bring	Expert opinion
10.6 Explain that the test is free	Expert opinion
10.7 Mention that a separate top is appropriate to wear instead of a dress	Suggestive
11. Test procedure	
11.1 Explain how the test is performed (handling and positioning of breast)	Definite
11.2 Explain how long the test takes	Definite
11.3 Mention whether the woman can bring someone to the appointment	Definite
11.4 Mention the gender of radiographers and staff	Expert opinion
11.5 Mention that screening staff are happy to answer questions	Definite
11.6 Mention that screening staff may ask personal history questions	Definite
11.7 Explain who reads the tests	Expert opinion
11.8 Explain double readings	Expert opinion
12. Test results	
12.1 Explain how to obtain the results	Definite
12.2 Mention approximate waiting time for results	Definite
12.3 Explain the meaning of the results	Definite
12.4 Mention benign breast abnormalities	Definite
12.5 Explain residual low risk not no risk of developing cancer	Definite
12.6 Mention when and how woman will be contacted about next appointment	Suggestive
13. Further tests	
13.1 Mention further assessment	Definite
13.2 Describe further assessment	Expert opinion

14. Treatment		
14.1	Mention available treatments	Definite
14.2	Describe available treatments	Expert opinion
14.3	Mention high quality treatment	Current practice
14.4	Mention the possibility of inclusion in a treatment trial	Definite
14.5	Mention the likelihood of treatment being effective	Suggestive
15. Preventative information		
15.1	Mention the possibility of interval cancers	Current practice
15.2	Include <i>Five Point Breast Awareness Code</i>	Current practice
15.3	Advise women to see a doctor if breast symptoms/changes occur	Current practice
16. Further information		
16.1	Explain where the woman can get further information	Expert opinion
16.2	Provide a name/telephone number and provide names of organisations/books	
17. Publication information		
17.1	Evidence base for leaflet	Expert opinion
17.2	Year of publication	Expert opinion
17.3	Sender/organisation identification	Expert opinion

HRT, hormone replacement therapy; NPV, negative predictive value; PPV, positive predictive value.

Table 6 Recall leaflet: summary of recommendations

Main issues	Overall recommendations
Outcomes	
1. Meaning of the result	
1.1 Give a clear reason for recall; exclude 'for a variety of reasons tests have to be repeated'	Screening standard
1.2 Mention technical errors	Definite
1.3 Include 'being recalled is part of routine (or second stage) screening'	Screening standard
1.4 Include 'most women recalled are found to have normal breasts'	Screening standard*
1.5 Include 'a substantial number of women are recalled'	Screening standard
1.6 Provide the proportion of screened women who would be recalled	Suggestive
1.7 Mention future risk of developing breast cancer – is it higher if you are recalled or found to have a benign condition?	Definite
1.8 List benign conditions that may be seen on mammograms	Definite
Difficult terminology includes 'benign', 'calcium spots', 'calcium deposits', 'calcifications' and 'cysts'	
1.9 Mention false positives	Definite
1.10 Mention false negatives	Definite
1.11 Avoid saying 'not to worry', 'not to be alarmed'	Screening standard
1.12 Avoid saying 'x-rays have been unclear'	Screening standard
1.13 Avoid the words 'something wrong', 'cancer', 'treatment' or 'abnormality'	Screening standard
1.14 Avoid using the term 'hospital'; use 'centre', 'unit' or 'clinic'	Screening standard
1.15 Avoid 'nurse counsellor' use 'breast care nurse'	Screening standard
2. Appointment information	
2.1 Explain how to get to the assessment centre	Screening standard*
2.2 Mention who may accompany the woman to the appointment	Screening standard
2.3 Explain how to change the appointment	Screening standard
2.4 Mention how long the appointment will take	Screening standard*
2.5 Mention who the woman will see at the assessment centre	Screening standard
2.6 Mention that screening staff are happy to answer questions	Suggestive

3. Test procedure	
3.1 Describe what tests will be carried out	Screening standard
3.2 Do not provide a detailed description of fine needle aspiration; instead, indicate that a 'sample will be taken'	Screening standard
3.3 Use the term 'biopsy' with caution	Suggestive
4. Test result	
4.1 Say how and when the results will be available	Screening standard
5. Follow up	
5.1 Mention that follow up may be necessary	Definite
6. Further information	
6.1 Explain how to get further information	Screening standard
7. Other information	
7.1 Do not send letter to be received on a Saturday	Screening standard
7.2 Minimise waiting time for appointment	Screening standard

*Recommendation retained as 'Screening standard' following review of the references in the original report.²⁰

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