

**CEASING WOMEN FROM THE NHS
BREAST SCREENING PROGRAMME**

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INTRODUCTION

1. Ceasing a woman from the call/recall system has the effect of stopping all invitations for breast screening from being sent to a woman. Her name will remain on the prior notification list (PNL) in the 'ceased' section, but she will not be invited for screening unless action is taken to revert her status to 'normal' on the call/recall system.
2. The breast screening programme *Statistical Bulletin 2000–01* shows that 8700 women in England aged 50–64 were ceased from call and recall.¹
3. Current guidance is that a woman may only be ceased from the breast screening programme if she:
 - has had a bilateral mastectomy
 - is terminally ill
 - has made her own informed choice that she no longer wishes to be invited for breast screening.
4. In all other circumstances, women should be sent an invitation for breast screening and given the opportunity to make an informed choice about whether to accept on each and every occasion when screening is offered.

BILATERAL MASTECTOMY

5. A woman should be ceased from the screening programme at PNL stage if she has had a prophylactic bilateral mastectomy or a bilateral mastectomy because of breast cancer. Either the GP or the breast screening unit may do this if they are aware, and have documentary evidence, that a woman has had a bilateral mastectomy.

WOMEN WITH A TERMINAL ILLNESS

6. Women in this situation should be treated in the same way as women who do not have a terminal illness for as long as possible. This includes being invited for breast screening as long as they are well. It is then the woman's decision whether to attend or not. At the GP's discretion, invitations might be postponed or ceased depending on the individual woman's situation and if, in the judgement of practice staff, an invitation for breast screening would cause unnecessary distress.

INFORMED CHOICE

7. There will be women who ask not to receive future invitations for screening. In these circumstances, the health professional to whom she has made her wishes known should ensure that the woman has received sufficient information to enable her to make an informed choice. The woman should confirm her decision in writing. These women should be ceased from the programme and no longer be sent invitations, as required under the *Data Protection Act*.²

WOMEN WITH DISABILITIES

Physical disabilities

8. Some women's physical disabilities may prevent them from achieving a position where a diagnostic mammogram can be taken. Every effort should be made to image women with a physical disability and to produce films of diagnostic quality. However, some women may have physical disabilities that prevent this. These include limited mobility in their upper bodies, inability to support the upper body unaided or inability to remain sufficiently still while the exposure is taken. Women should not automatically be ceased from the programme for these reasons. In these circumstances, it is recommended that the situation should be explained to the woman individually and that she should be ceased from the programme only if the disabilities are unlikely to improve and at her request or with her informed, written consent.

Learning disabilities

9. Learning disabilities alone are not a reason for ceasing women from the programme. Materials are now available to assist women with learning disabilities to make an informed choice about whether or not to participate in the programme.³⁻⁵ There will, however, be a small number of women who are unable to consider the concept of participation in the programme and who become very distressed when the procedure is attempted. In these situations, all attempts to take a mammogram should stop and the situation should be reconsidered at the next routine invitation. Women with learning disabilities have the same entitlement as other women to breast screening and should not automatically be ceased from the programme for this reason.

Ionising Radiation (Medical Exposure) Regulations 2000

10. The *Ionising Radiation (Medical Exposure) Regulations 2000* (IRMER) require the IRMER practitioner to justify the medical exposure.⁶ The practitioner (usually a radiologist, breast clinician or radiographer) justifies a medical exposure in terms of the potential diagnostic benefit, taking into account any detriment the exposure may cause to the individual (*Guidance Notes for the Implementation of the Ionising Radiation (Medical Exposure) Regulations 2000 in the NHS Breast Screening Programme*⁷). The practitioner may therefore decide not to proceed if it is not possible

to obtain a mammogram of diagnostic quality. This should be regarded as a failure to justify the exposure on this occasion only. Circumstances may change and the woman is still entitled to receive invitations for breast screening. The decision on whether the exposure is justified must be made on each occasion that the woman attends for screening.

Ultrasound

11. Ultrasound is not a technology suitable for breast screening and should not be regarded as an alternative. It should not be offered to women who are unable or unwilling to undergo mammography nor should a request from a woman in this position be met positively. Women should be advised to be breast aware. If a woman has a regular carer who sees the woman undressed then the carer should be informed about what signs and symptoms may be observed and that these should be reported.

Clinical examination of the breast

12. *PL/CMO(98)1* of February 1998⁸ (also issued as *PL/CNO(98)1*) advised that palpation of the breast by either medical or nursing staff should not be included as part of routine healthcare for women. Therefore, it should not be offered as an alternative to mammography to women who are unable or unwilling to undergo mammography nor should a request from a woman in this position be met positively. Women should be advised to be breast aware. If a woman has a regular carer who sees the woman undressed then the carer should be informed about what signs and symptoms may be observed and that these should be reported.

BREAST IMPLANTS

13. Breast screening by mammography is not appropriate for women who have implants because of reconstruction after bilateral subcutaneous mastectomy if there is no breast tissue remaining. These women should be advised that they will be ceased from routine screening. Women with cosmetic implants should be screened at the same intervals as other eligible women.

PREVIOUS BREAST SURGERY

14. Women who have breast tissue remaining after surgery for benign or malignant conditions should continue to be invited for screening at routine intervals.

GENDER REASSIGNMENT

15. Individuals who are undergoing female to male gender reassignment should continue to be invited for breast screening so long as they are registered as a woman or indeterminate, unless they ask to be ceased from the programme or have had a bilateral mastectomy. Individuals who are undergoing male to female gender reassignment may be screened as a self referral at the request of their GP while still registered as male. Individuals who are registered as indeterminate or female are included in screening batch lists and will be sent a screening invitation unless they ask to be ceased from the programme.

MAMMOGRAPHY OUTSIDE THE NHS BREAST SCREENING PROGRAMME (NHSBSP)

16. Women who have had mammography outside the NHSBSP remain eligible for screening and should not be ceased from the screening programme. They should continue to be sent an invitation for screening at the routine interval so that they can decide whether or not to accept.

MAKING A DIFFERENCE: REDUCING GENERAL PRACTITIONER PAPERWORK

17. Since the publication of this Cabinet Office document in April 2001, within general practice staff other than GPs have been allowed to sign off the PNL.⁹ However, it is recommended that only a GP or practice nurse should cease a woman from the breast screening programme.

SUMMARY

18. A woman should only be ceased from breast screening call and recall if she:

- has had a bilateral mastectomy
- is terminally ill and a screening invitation would be distressing
- has made her own informed choice that she no longer wishes to be invited for breast screening.

Women must be ceased from call and recall if they make an informed choice that they no longer wish to be invited for breast screening and they make a written request that this should happen.

19. The following women should not be automatically ceased from breast screening call and recall:
- women with breast implants
 - women who have had previous breast surgery
 - terminally ill women
 - women with physical disabilities
 - women with learning disabilities.
20. Within general practice, staff other than GPs have been allowed to sign off the PNL. However, it is recommended that only a GP or practice nurse should cease a woman from the breast screening programme.
21. Primary care trusts (PCTs) and primary care agencies operating the call and recall system should act only if valid reasons for ceasing a woman are cited.
22. PCTs should be asked to audit the call/recall status of all ceased women at least annually to verify that they have been ceased for valid reasons.

REFERENCES

1. *Statistical Bulletin Breast Screening Programme, England 2000–01*. Department of Health, 2002 (Bulletin 2002/01).
2. *Data Protection Act 1998*. The Stationery Office.
3. *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities*. NHS Cancer Screening Programmes, 2000 (NHSBSP Publication No 46).
4. *Looking After My Breasts*. Gaskell/St George's Medical School, 2000. Available from Book Sales, Royal College of Psychiatrists.
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6. *Ionising Radiation (Medical Exposure) Regulations 2000*. The Stationery Office.
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8. *Clinical Examination of the Breast*. Department of Health, 1998 (Professional Letter PL/CMO(98)1; also published as PL/CNO(98)1).
9. *Making a Difference: Reducing General Practitioner Paperwork*. The Cabinet Office, 2001.