

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

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INTRODUCTION

1. Ceasing a woman from the NHS Cervical Screening Programme (NHSCSP) has the effect of stopping all invitations being sent to a woman and removing her name permanently from prior notification lists (PNLs). There are two clear categories where this takes place (age and no cervix), but there are also a number of other reasons why a woman is ceased.
2. *Making a Difference: Reducing General Practitioner Paperwork*¹ states that GPs no longer have to sign off PNLs themselves. However, there are some areas where it is recommended that a GP or practice nurse should oversee a particular woman's management.
3. The cervical screening programme's *Statistical Bulletin 2001–02*² shows that the number of pre-menopausal women in England who were ceased from recall for reasons other than absence of cervix or age are:

Age 20–29	3 900 women
Age 30–39	13 000 women
Age 40–49	22 900 women
Age 50–59	42 600 women

INFORMED CHOICE

4. There will be women who ask not to receive invitations for cervical screening and who therefore wish to be 'ceased' from the programme. In these circumstances, the health professional should ensure that the woman has received sufficient, accurate information to make an informed choice and that she has expressed the desire to be ceased in writing (*Consent to Cervical Screening*³). The *Data Protection Act 1998*⁴ will also require that women who have expressed a clear desire to be ceased from the programme should no longer receive invitations and that they should be ceased from the invitation schedule.
5. Women who have never had sex with a man are likely to be at very low risk of developing cervical disease. However, this status is difficult to ascertain and circumstances may change. In addition, these women are entitled to receive a cervical screening invitation. They should make an informed choice about whether to accept the invitation or not on each occasion that it is offered and they must not be ceased from the programme except at their request.

AGE

6. A woman should continue to be screened at least every five years until her 65th birthday. Once she is 60 or over, she may be ceased from the programme providing her history makes her suitable for this, ie her last three consecutive tests (including the final one) have been reported as negative. Any inadequate test should be repeated as per normal practice.
7. Women whose last three tests include an abnormal result should be retained in the programme until any necessary treatment and/or surveillance episode has been concluded and it is deemed safe by their gynaecologist/GP to return them to routine management. They should continue in the programme beyond their 65th birthday if necessary.
8. Women who have reached the age of 65 and who have never had a screening test will have failed to respond to several invitations. It is recommended that they may therefore be ceased when they reach the age of 65. This may also apply to women who did not respond to their last invitation. However, these women may be screened opportunistically if appropriate or if they later request a test.

HYSTERECTOMY

9. Only women with a total hysterectomy should be ceased. Women with a subtotal hysterectomy who have retained their cervix should remain in the programme since they continue to be at risk. Women who have a female to male sex change will also usually have a total hysterectomy. Women who have had a total hysterectomy should be advised that they will be removed from the cervical screening call/recall system.

MALE TO FEMALE SEX CHANGE

10. These people may be on the register as female. However, since they have no cervix, they are not eligible for the programme, nor are they at risk. They should be ceased from the programme, and it is recommended that the 'absence of cervix' marker should be set.

CONGENITAL ABSENCE OF CERVIX

11. Women born with this abnormality are not at risk and are therefore not eligible for the programme. The 'absence of cervix' marker should be set to cease them.

WOMEN WITH A TERMINAL ILLNESS

12. 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 cervical 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 cervical screening would cause unnecessary distress.

RADIOTHERAPY

13. It is usually impossible for an accurate report to be made following radiotherapy for cervical cancer and follow-up should therefore be gynaecological rather than cytological. These women should be ceased from the programme and any tests taken should be given an H code, ie no recall date.

CIRCUMCISED WOMEN

14. It has been suggested that women who have undergone circumcision should be automatically ceased from the programme. However, most of these women will be capable of intercourse and remain at risk of cervical cancer. Nevertheless, taking of the cervical sample, even handled sensitively, may not be possible. It is recommended that a woman in this situation should be considered individually and only ceased from the programme at her request or with the woman's informed, written consent.

WOMEN WITH DISABILITIES

Physical disabilities

15. Some women's physical disabilities may prevent them from achieving a position where the cervix can be visualised and a cervical sample can be taken. This may include women with severe arthritis or very obese women who are known to have been 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 only be ceased from the programme at her request or with her informed, written consent.

Learning disabilities

16. 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.⁵⁻⁷ 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 cervical sample should stop and the situation reconsidered at the next routine invitation.

MEDICAL/CLINICAL REASONS

17. This is considered too vague a term to be a reason for ceasing women, and it is recommended that it is no longer used or accepted as a valid reason.

SUMMARY

18. Women should only be ceased from cervical screening call and recall as follows:

- following the first test after their 60th birthday only when their last three consecutive tests have all been negative
- persistent non-responders should be ceased from recall on their 65th birthday
- women who have undergone radiotherapy for cervical cancer
- the 'absence of cervix' marker is used for
 - women with a total hysterectomy
 - male to female transsexuals
 - congenital absence of cervix.

19. The following women should not automatically be ceased from cervical screening call and recall:

- women who have never had sex with a man
- terminally ill women
- women who have been circumcised
- women with physical disabilities (including severe arthritis and obesity)
- women with learning disabilities
- when 'clinical' or 'medical' reasons alone are cited.

20. Women must be ceased from call and recall if they make an informed choice that this is what they want and if they sign a written request that this should happen.

Ceasing Women from the NHS Cervical Screening Programme

21. Primary care trusts (PCTs) and agencies operating the National Health Application and Infrastructure Services (NHAIS) (Exeter) cervical screening system should not act when 'clinical' or 'medical' reasons alone are cited unless further explanation is provided.
22. It is advised that the GP's or practice nurse's attention should be drawn to any instance of ceasing before the PNL is 'signed off' for anything other than routine changes of address etc. This includes women covered by paragraph 18 above, and either the GP's or practice nurse's signature would be acceptable in these cases. The GP him/herself must approve ceasing of any women covered in paragraph 19 above and should sign to record this decision.
23. PCTs should be asked to review women who already have been ceased from the programme for reasons other than age or absence of cervix. This should be done through clinical governance arrangements.

REFERENCES

1. *Making a Difference: Reducing General Practitioner Paperwork*. The Cabinet Office, 2001.
2. *Cervical Screening Programme, England Statistical Bulletin 2001–02*. Department of Health, 2002 (Bulletin 2002/21).
3. *Consent to Cervical Screening*. NHS Cervical Screening Programme, 2000 (Occasional Report 00/1).
4. *Data Protection Act 1998*. The Stationery Office.
5. *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities*. NHS Cancer Screening Programmes, 2000 (NHSCSP Publication No 13).
6. *Keeping Healthy 'Down Below'*. Gaskell/St George's Medical School, 2000. Available from Book Sales, Royal College of Psychiatrists.
7. *Having a Smear Test*. NHS Cancer Screening Programmes, 2000. A picture leaflet for women with learning disabilities.