



Screening Matters

ISSN 1176-7634

The National Screening Unit Newsletter

ISSUE THREE February 2005

Health (National Cervical Screening Programme) Amendment Act 2004

Editorial



Karen Mitchell
Group Manager
National Screening Unit

This is the second issue of Screening Matters to focus on improvements to the National Cervical Screening Programme that come into effect March 2005.

In the previous special edition, we looked at evaluation and quality improvement and how the Health (National Cervical Screening Programme) Amendment Act 2004 supports and strengthens our activities in this area. In this edition we focus on the practicalities of the changes and their impact on both women and smear takers.

Preparation for the implementation of the new Act has taken over a year and required the input of a large number of people. Significant changes will occur to a number of areas including policy, operating protocols and standards, IT systems, NCSP-Register letters, and key information and resources for women. Consultation on these changes has been ongoing over the past year and has included Advisory Groups, screening service providers and consumer groups.

I would like to take this opportunity to thank all of those people who have given their time, energy and support to help us with these changes. I look forward to the implementation of the Act and ultimately better outcomes for all women.

Since the last newsletter the Cervical Cancer Audit, an independent audit of the National Cervical Screening Programme was released in November 2004. This audit concluded the Programme operates to a generally high standard for women having regular smears and that women and health professionals can have confidence in the services and should be encouraged to participate in the Programme. The audit found some women are not being screened regularly and in particular Māori and Pacific women.

The audit provides a call to action for the Programme, for providers and for women, and reinforces one of our most important Programme messages – regularly three yearly screening is a woman's best protection against cervical cancer.

Updated NCSP Resources

The new changes have required the revision of two of the NCSP Resources. The two resources are:

1. The general pamphlet, (code 1256) – “Cervical Smears – What women need to know.” These should be given to all women when they have their first smear and/or join the Programme
2. The detailed booklet (code 1328) “Cervical Screening – A guide for women in New Zealand.” This is available to be given to any woman who wants more detailed information about cervical screening, the Programme or cervical cancer.

These updated resources will be available from February 20 and can be ordered:

1. Online at website www.healthywomen.org.nz. Go to the health professional section then Health Education Resources
2. From your authorised Ministry of Health, Health Education Resource Provider.

It is important the updated resources are not confused with the existing ones. They look the same however can be distinguished by the print date **March 2005** which is located on the back panel underneath the Ministry of Health Logo. Please dispose of all existing resources, preferably by paper recycling, before stocking the updated versions.

The NCSP-Register

The NCSP-Register is a fundamental part of the Programme. This national computer system holds the details of women enrolled in the Programme, as well as details of smear takers, specialists and laboratories. For security, the NCSP-Register is separate from any other computer system. Women's records include their name, address, age, ethnicity, usual smear taker and clinic, and her cervical results. If a woman needs treatment, the NCSP-Register also tracks her steps through the treatment process.

It is from this computer system that the Programme produces the letters that welcome women to the programme, remind them if they are a few months overdue for their next cervical smear, tell women if their latest result was not normal, and tell women that they no longer need to have cervical smears. These letters are a back up for GP and laboratory recall systems. NCSP-Register data is also used to help monitor the Programme.

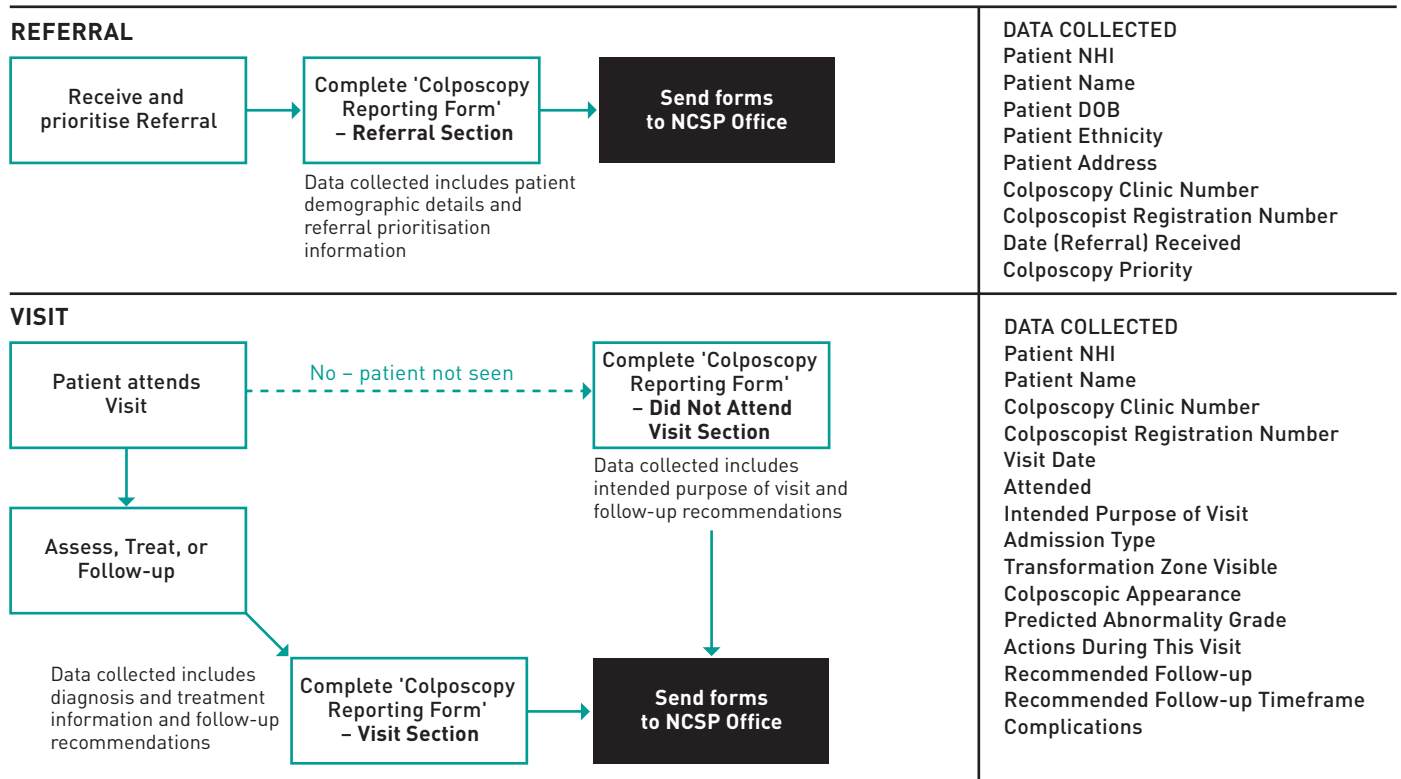
After March 2005, if women withdraw from the Programme, the NCSP-Register will hold only their name, address, date of birth and National Health Index number, ethnicity and the date they withdrew.

Colposcopy Reporting

This new legislation requires all colposcopists, both public and private, to report to the National Cervical Screening Programme on each colposcopy referral and procedure. The colposcopy report will play a vital part in the clinical management of women and evaluation initiatives. The data to be collected and the proposed process is presented in the diagram below.

Documentation has been developed and will be included in an information pack to be sent to all colposcopists. Colposcopy reports will be sent to the NCSP-Register on a regular basis and can be on paper forms (for each patient) and from July 2005, there will be an electronic interface between the colposcopists computer system and our computer system.

PROPOSED DATA COLLECTION PROCESS



Nurse Smear Takers

Nurse smear takers should use their own registration number rather than using a doctors one.

Historically nurse smear takers who were taking cervical smears, but not certified, have had those smears recorded under the Registration number of a Medical Practitioner. The Health Practitioners Competency Assurance Act 2003 is clear that the Registered Health Professionals in each case are professionally and personally liable for the outcome of their individual actions at all times.

This means that a Registered Medical Practitioner cannot legally assume, wholly or partially, professional responsibility for the actions of a Registered Nurse where those actions have been carried out solely by the Registered Nurse in the course of their normal duties. Changes will be made to the NCSP-Register to allow the training status of Nurses to be recorded on the system. This allows those Nurses who have previously used a Medical Practitioners number to use their own registration number.

The changes to the NCSP-Register will also allow a greater level of smear taker monitoring at both the national and individual smear taker level. Monitoring smear taker performance will assist the NCSP in

delivering a safe and effective programme and is in line with the requirements of the NCSP Training Standards for Smear Takers – May 2002.

The NCSP is fully committed to ensuring that the smear taking service provided to New Zealand women is of the highest quality possible. To this end the NCSP has made available a smear taker training grant to allow more nurses to undertake this training.

To be registered on the NCSP-Register as a nurse smear taker, simply ring the Programme on freephone 0800 729 729 and provide your registration number.

Green Opt Off Stickies

With the changes to the Programme, these stickies are no longer used and will no longer be available. Please note that even if they are still used, the lab is required by law to send all results to the Programme. The Programme will upload all results onto the NCSP-Register, unless a woman herself (not her GP) has formally withdrawn from the Programme in writing. Other articles in this newsletter give more information on enrolment and withdrawal from the Programme.

How do the changes affect Smear takers including Colposcopists?

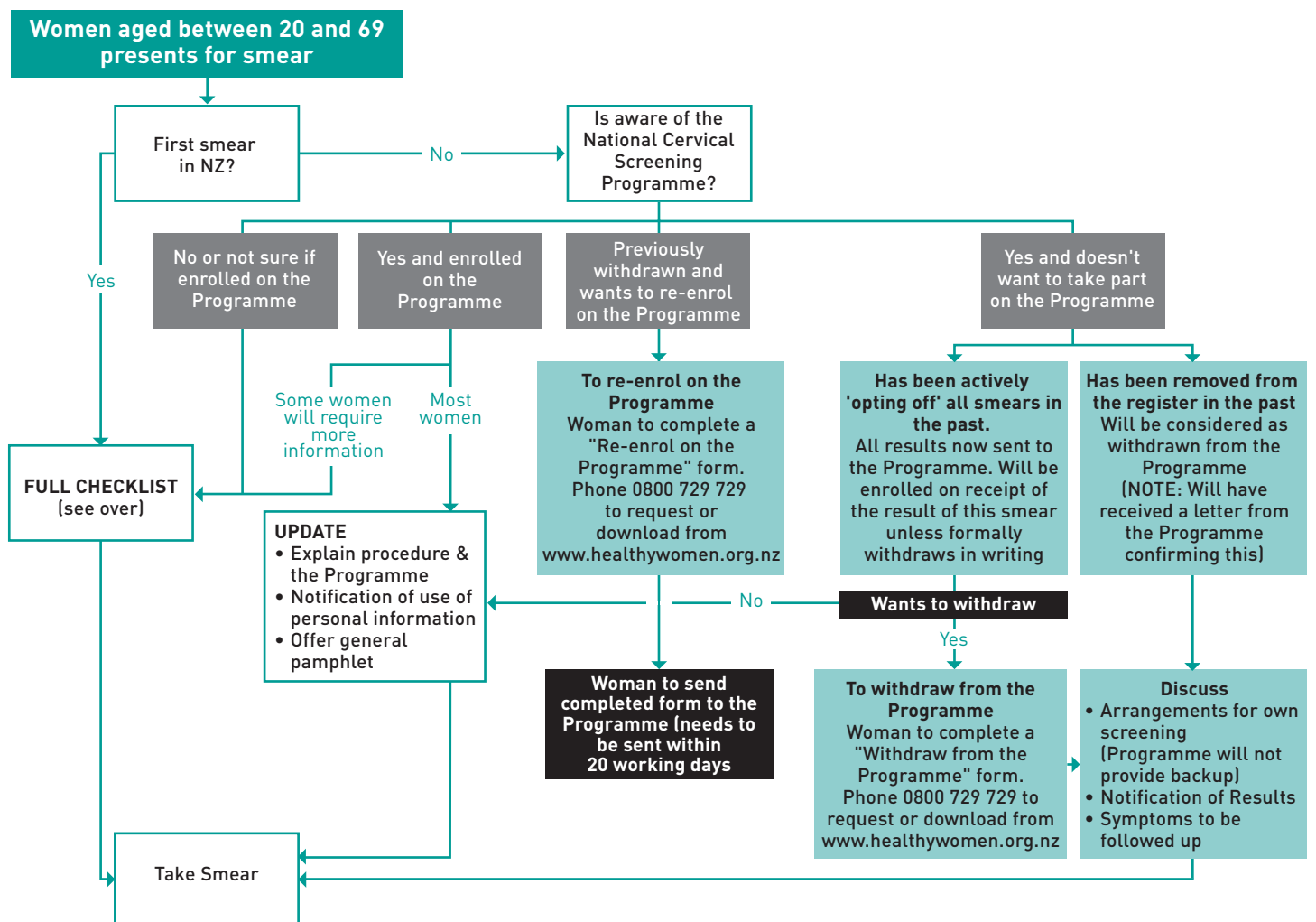
Key points from the Legislation

- Responsibilities to inform women are clearly outlined (see next column)
- All cervical results are sent by the laboratory to the NCSP
- Results are entered onto the NCSP Register and all women are enrolled unless a woman withdraws from the Programme in writing
- A full screening record must be kept on the Programme so there is no longer the ability to 'opt off' individual results. A woman is either enrolled or has withdrawn herself from the Programme
- Programme Evaluators are able to access other personal health records relevant to that woman. This can be done for the purposes of evaluation for any woman who develops cervical cancer regardless of whether or not they are enrolled in the Programme. A smear taker is able to oversee an evaluator, when accessing personal health records.
- The Act allows for the prescribing of standards which may be enforced if required.

Smear taker Responsibilities

- Explain the procedure
 - Provide information regarding:
 - the importance of regular cervical smears
 - the objectives of the National Cervical Screening Programme
 - the benefits and limitations of cervical screening
 - the benefits of participating in the Programme
 - who has access to information on the NCSP-Register and uses that information may be put to
 - Advise women that the laboratory sends all cervical results to the Programme and these are entered onto the NCSP-Register. All women are automatically enrolled unless they formally withdraw
 - Explain how they withdraw from the Programme
- This information is contained in the general pamphlet "Cervical smear tests – What women need to know".

SMEAR TAKER FLOWCHART



Smear Takers Checklist

Have you explained?

Yes

- | | |
|---|--------------------------|
| 1. The importance of regular cervical smears.*† | <input type="checkbox"/> |
| 2. The procedure for taking a cervical smear.*† | <input type="checkbox"/> |
| 3. The objectives of the National Cervical Screening Programme (NCSP).*† | <input type="checkbox"/> |
| 4. The benefits and limitations of cervical screening.*† | <input type="checkbox"/> |
| 5. The benefits of participating in the Programme.*† | <input type="checkbox"/> |
| 6. What symptoms need to be followed up even with a normal result.† | <input type="checkbox"/> |
| 7. Automatic enrolment in the Programme.*† | <input type="checkbox"/> |
| 8. What information is collected, who has access to it and what it is used for.*† | <input type="checkbox"/> |
| 9. How the Programme is evaluated including evaluators' ability to access personal health records.† | <input type="checkbox"/> |
| 10. The ability to withdraw from the Programme and how.*† | <input type="checkbox"/> |
| 11. How the woman will be notified of her results including a normal result. | <input type="checkbox"/> |
| 12. When her next smear will be due and the practice recall system. | <input type="checkbox"/> |
| 13. Have you given the woman a copy of the general pamphlet? | <input type="checkbox"/> |

*Legislative Requirement

†Please refer to the General Pamphlet – "Cervical smear tests – What women need to know" for further information.

Useful Resources

Available from www.healthywomen.org.nz

Or from your authorised Ministry of Health, Health Education Resource Provider

1. General Pamphlet (code 1256) "Cervical smear tests - What women need to know". This resource should be given to all women and covers all of the above information.
2. Detailed booklet (code 1328) "Cervical Screening – A guide for women in New Zealand" is available to any woman who wants more information.
3. Website www.healthywomen.org.nz provides more information for both women and smear takers.
4. Guidelines for the Management of Women with Abnormal Cervical Smears – 1999.
5. NCSP Operational Policy & Quality Standards, October 2000.



National Screening Unit

Level 3, Unisys Building, 650 Great South Rd
Penrose, Auckland, New Zealand
Phone: +64 9 580 9000 Fax: +64 9 580 9001

Old Bank Building, 102 Customhouse Quay
Wellington, New Zealand
Phone: +64 4 495 4400 Fax: +64 4 495 4401

www.healthywomen.org.nz
A SEPARATE UNIT OF THE MINISTRY OF HEALTH

www.healthywomen.org.nz

How do the changes affect Women?



Hazel Lewis
Clinical Leader
National Cervical
Screening Programme

A letter is being sent later this month to all women enrolled on the Programme to explain how the changes in the Act will affect them. This letter covers the Programme and its objectives, the benefits and limitations of being on the Programme and how they may cancel their enrolment. The letter is accompanied by Questions and Answers which cover the most commonly asked questions about cervical screening and the National Cervical Screening Programme.



Jane McEntee
Programme Manager
National Cervical
Screening Programme

QUESTIONS AND ANSWERS ON CERVICAL SCREENING, AND THE NATIONAL CERVICAL SCREENING PROGRAMME (NCSP)

What changes are being made to the National Cervical Screening Programme?

Under the Health (National Cervical Screening Programme) the following changes are being made:

- making it clear who is responsible for running the Programme
- making it clear what the responsibilities are of smear takers, laboratories and gynaecologists
- making sure you get the information you need about cervical screening and the Programme
- recording and monitoring all cervical smear results so there is a more complete personal screening history, by changing the option of withdrawing from the NCSP-Register for individual smears (opting-off) to the option of withdrawing from the Programme
- allowing access to personal health records by trained evaluators (without additional consent) so that they can fully evaluate the Programme
- ensuring protection of confidentiality of women's personal health records at all times
- providing for regular external independent review of the Programme

What are the benefits of cervical screening and the National Cervical Screening Programme?

The benefits of participating in the Programme include:

- There will be a record of your screening history. This information can be used by your smear taker or the laboratory to advise appropriate follow-up and when to have your next smear test.
- You will receive a letter welcoming you to the Programme. This letter will include the result of your first cervical smear taken within the Programme.
- You will receive a reminder if your smear test is a few months overdue.
- If you have a smear test that is not normal, you will receive a letter from the Programme.
- If you had an abnormal smear, the Programme provides a back-up system to check that you received the

appropriate follow-up investigation and/or treatment.

- You will receive a letter to inform you when you no longer need to have cervical smears.
- You will receive a copy of any of your own information that you ask for.
- There are minimum quality standards that all providers associated with the Programme should comply with.
- You will help make it a success for all New Zealand women. High numbers of women must take part to enable the Programme to work well and achieve its aims.

What are the limitations of cervical screening?

Cervical smear tests are a very good screening tool, but like all screening tests, they are not perfect. Sometimes, abnormal cells are missed. This can happen because:

- a cervical smear did not contain any abnormal cells even though some were present on the cervix
- abnormal cells were hidden by blood or mucus so they could not be seen under the microscope
- cells with very slight changes were hard to interpret as either normal or abnormal
- abnormal cells were missed by the person reading the smear
- very occasionally, cancer may have already developed.

However, changes to cervical cells happen very slowly.

If women have another smear in three years time, it is very likely that the abnormal changes will be found. They can then be treated if necessary.

Occasionally a result says a woman has some abnormal cells when she doesn't. If a woman has been told her smear is abnormal, she will have a further smear or be referred to a specialist for an examination called colposcopy. The results from these will show no cervical abnormality.

Do I have to take part in the National Cervical Screening Programme?

No. You can decide at any time that you do not want to take part in the cervical screening Programme and withdraw by filling in the Programme's "Withdraw from the >>

Programme” form or by writing to the Programme. These forms will be available from 7 March 2005 by phoning the National Cervical Screening Programme freephone 0800 729 729 or on the website www.healthywomen.org.nz

It is important to note that if you withdraw from the Programme then you and your smear taker will be responsible for your cervical screening. The Programme will not follow up your smear results or track your smear history.

The cervical screening programme is now required to delete from the NCSP-Register all results of women who withdraw from the Programme.

If after withdrawing I change my mind can I return to being on the cervical screening programme?

Yes. You can re-enrol at any time by filling in a form or writing to the Programme. If you re-enrol, your smear history will start with your most recent smear.

What personal health information does the cervical screening programme receive?

The information received by the National Cervical Screening Programme includes your personal and contact details, screening results and any treatment details. This information is used to help decide when you need to have your next smear, whether you need follow-up, and to send you a letter if you are overdue for a smear or need follow-up.

Your smear taker will ask which ethnic group you belong to and this is recorded on the NCSP-Register and is used to plan better services.

Is my information confidential?

Yes. The information is stored on the NCSP-Register, a computer system that is held by the National Screening Unit of the Ministry of Health in Wellington. Your information is protected by the new law and is confidential. It can only be released outside the Programme to your health practitioner(s), evaluators, and a review committee to check how well the Programme is working.

The **National Kaitiaki Group** has been set up by law to protect the use of Maori women’s summary information (information that will not personally identify anyone) stored on the NCSP-Register. The new law does not affect the Kaitiaki Regulations.

The **Pacific Women’s Data Advisory Group** advises on the use of Pacific women’s summary information (information that will not personally identify anyone) stored on the NCSP-Register.

What does evaluation mean?

Evaluation means checking that all aspects of the cervical screening programme are working as they should.

Why is evaluation of the National Cervical Screening Programme important and what has changed?

- It is important that the Programme can be fully evaluated to ensure it is safe for you and other women while maintaining your right to privacy.
- Evaluators with appropriate training and experience will be appointed by the Director-General of Health to do the evaluations.
- Evaluators will need to access a small number of women’s personal health records held by smear takers to look at what smears a woman has had, how often, the number of smears and the results of those smears. Evaluators may also look at laboratory and colposcopy reports to get this information.
- The new law has improved access to records to assist with evaluation of the Programme. Personal health records can help evaluations by showing how often a woman had smears, how abnormal smears were managed and finding out whether a cervical smear had ever been offered.
- Evaluators will be bound by law to follow strict confidentiality rules to make sure any information accessed in a woman’s records is only used for the evaluation of the Programme. In addition, smear takers will be able to supervise the evaluators’ access to personal health records to further ensure privacy is safeguarded.
- Evaluation reports, which will not identify individual women, will be published so women participating in the Programme can see how well it is working.

Can evaluators access my records if I have withdrawn from the National Cervical Screening Programme?

Yes. Evaluations will include women who develop cervical cancer whether or not they are enrolled in the Programme because this is an important aspect of evaluation.

Where do I go if I have more questions?

If you would like to know more about cervical smears, cervical cancer or the National Cervical Screening Programme, ask your doctor or smear taker for a copy of the free booklet **Cervical Screening – A guide for women in New Zealand**.

You can also visit our website www.healthywomen.org.nz or contact:

- The National Cervical Screening Programme freephone 0800 729 729
- Your own doctor or practice nurse
- A local women’s centre or health centre
- Your local Family Planning Centre
- Your local Cancer Society.