# **Cervical smears** – achieving equity

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# **Key concepts**

- Target Māori, Pacific and Asian women and women from areas of high deprivation for cervical screening
- Target women over 30 years who have never had a smear or have not had a smear for over five years
- Target interventions carefully to avoid increasing disparities



Following the introduction of the National Cervical Screening Programme (NCSP) in 1990, the overall incidence of cervical cancer in New Zealand has dropped dramatically. Cervical cancer is a disease with a long latency period, taking on average 10 to 20 years to develop. This means that screening for the detection and treatment of precursor lesions can be very effective for women who participate regularly in a screening programme.

An inadequate screening history is associated with increased rates of cervical cancer. A 2004 audit of women with cervical cancer in New Zealand demonstrated that 80% had a suboptimal screening history.<sup>1</sup> Although it is anticipated that the HPV vaccination programme will bring about a further reduction in cervical cancer rates in the future, improving screening rates will continue to be the most effective way to reduce morbidity and mortality from cervical cancer.<sup>2</sup>

# Many women are not participating in cervical screening

The NCSP has a target of 75% coverage for cervical smears for all eligible women.<sup>3</sup> At this stage European/Other women are the only ethnic group who meet this target (Figure 1), although screening rates are increasing for all ethnicities.

The women who consistently have cervical screening rates less than the NCSP target are:

- Māori
- Pacific
- Asian
- Women from the most deprived areas

#### Māori women

As rates of screening have improved, the rate of cervical cancer in Māori women has fallen. However Māori women still have higher rates of cervical cancer than non-Māori women, and are four times more likely to die from cervical cancer than European women.<sup>4</sup> This is likely to be due to continued suboptimal rates of screening.

## Who should have cervical smears

All women who have ever been sexually active are eligible for cervical screening from the time they turn 20 until they turn 70. This includes:

- Lesbians
- Women who have not been sexually active for many years
- Women who still have a cervix following a hysterectomy

Women aged 70 and over who have never had a cervical smear test are advised to have a smear test followed by another a year later. If both tests are normal no further tests are needed.



**Figure 1:** National Cervical Screening Programme three year coverage by ethnicity, March 2009 (hysterectomy-adjusted)<sup>5</sup>

# Recommendations for screening following hysterectomy<sup>6</sup>

- Women who have had a total hysterectomy (the cervix has been removed) for a benign condition and have no history of abnormal smears do not need to continue to be screened.
- Women who have had a total hysterectomy and have had abnormal smear results or abnormal cervical histology need to continue being screened.
- Women who have had subtotal hysterectomies (the cervix has not been removed) need to continue being screened.

The screening interval will vary and depends on previous history. For further details, refer to the 2008 Guidelines for Cervical Screening in New Zealand.

#### **Pacific women**

Pacific women have a higher rate of cervical cancer than the national average, and are almost twice as likely to die from cervical cancer as European women. Uptake of cervical screening is lower for Pacific women than for European women, with just over half of eligible Pacific women having regular cervical screening.<sup>7</sup>

#### Asian women

Asian women are significantly less likely to have had cervical screening than European women, with less than half having regular cervical screening.<sup>8</sup> This is the lowest rate for any ethnic group in New Zealand.There are no published statistics on cervical cancer in Asian or Chinese immigrant women in New Zealand.

#### Women living in areas of high deprivation

Eligible women living in the most deprived areas of New Zealand are less likely than women living in the least deprived areas to have had cervical screening in the last three years.<sup>9</sup>

### **Mana Wahine**

The concept of mana wahine describes the status, power and authority of Māori women. Mana wahine reflects Māori women's connection to the land, as descendants of Papatuanuku, the Earth Mother. Mana wahine has embedded within it a philosophy concerning the sphere of influence, a code of knowledge and behaviour built up over generations. It is the intellectual property that belongs to all Māori women.

Māori women have a long history of trying to bring about changes in the provision of health services to Māori people (e.g. Māori Women's Welfare League). Services run by Māori for Māori may be more acceptable and appropriate for many Māori women. It is therefore important to raise the awareness of specific cervical screening services, that may be available in their own communities, and to ensure Māori women are fully informed of all available services.

Māori women are at the centre of their whānau, hapū and iwi and fulfill an important role in sustaining them. They are te wharetangata, the House of the People. The spiritual link between land and the health and wellbeing of Māori women is reflected in the language used to describe the functional anatomy of te wharetangata. The cervix is the doorway to te wharetangata. The relationship between women and land acknowledges that they carry the same role in terms of providing nourishment: without them humanity is lost.<sup>10</sup>

Me aro koe ki te hā o Hine-ahu-one Pay heed to the dignity of women

## PHO performance management programme and cervical screening

Cervical cancer screening coverage is included as one of the clinical indicators for the PHO performance management programme. This is important because regular cervical screening has been shown to result in a reduction in deaths from cervical cancer, but currently in New Zealand some women are receiving less than adequate levels of cervical screening.

The PHO indicator includes all women aged 20–69 years who have received a cervical smear in the last three years. A higher weighting is given to cervical smears performed in high needs women. High needs women is defined as an enrolee who is Māori, Pacific, or New Zealand deprivation deciles 9 or 10. The PHO enrolment database reports the New Zealand deprivation deciles 9 or 10 classification as Quintile 5.

The overall goal is to achieve a cervical screening rate of greater than 75% for all women. PHOs which initially have low coverage rates are expected to make more of an increase, than PHOs which start with coverage rates nearer to the target.

#### Make it count

**NHI number:** Ensure the NHI number is included. A valid NHI means the data can be matched with the National Screening Unit (NSU) and PHO enrolment databases, to ensure it is counted.

**Gender:** If the gender is recorded as "unknown" the record is accepted, however it is converted to "male" and will not be counted.

**Declines/withdrawals:** Women who withdraw from the programme and opt off the national register are not counted. This should not affect achievement of targets, as they are based on improvement rather than absolute numbers.

Hysterectomy adjustment: Targets have been developed taking into account the estimated number of women who have had a hysterectomy. Again, this should not affect overall achievement of targets, as they are based on improvement, rather than absolute numbers.

The full PHO indicator definitions are available from: www.dhbnz.org.nz/Site/SIG/pho/Programme\_ Documents.aspx

# Overcoming barriers to cervical screening

#### **Barriers**

There are many barriers that may explain the reluctance of some woman to attend for cervical screening. Some are common to all women, such as shyness or cost, while other reasons may be specific to some groups, such as cultural and language barriers.

#### Embarrassment/whakamā/shyness

For many women having a cervical smear is often associated with thoughts of nervousness, vulnerability and embarrassment.

Whakamā is thought to be one of the main barriers to screening for Māori women. This may be due to the strong Māori belief in the sacredness of te wharetangata, and a perceived insensitivity of smear takers.<sup>11</sup>

The association between sexual activity and cervical screening may make many women uncomfortable about presenting for a smear. Some women are also concerned that personal information of a sexual nature may not remain confidential. Traditionally Asian women are typically less

open about their sexuality and are generally discouraged from expressing their sexuality until they are married.<sup>12</sup>

Many women are embarrassed by having a smear performed by a male GP. Most Māori women feel more comfortable with a Māori smear taker, although Pacific women generally prefer a non-Pacific smear taker, who they would be less likely to know through their social networks.

#### Cost

Cost is frequently a barrier to having a cervical smear.<sup>11</sup> There is considerable variation within New Zealand in the cost of having a smear taken. Other cost issues include transport, childcare and wages lost due to taking time off work. In many cases when money is an issue, a test such as a cervical smear, becomes a low priority.

For women who are not enrolled in a PHO, the cost of a consultation is not subsidised, and their consultation will be charged at the "casual" rate.

#### Cancer fear

Although the fear of cancer is a motivating factor for many women, it is also a significant deterrent for others,<sup>11</sup> as many would rather not know. Different cultures have their own belief systems about cancer and illness.<sup>13</sup> These may act as a barrier for cervical screening, e.g. the belief that cancer means certain death, and there is little that can be done to treat it.

#### Pain or discomfort

Many women identify the pain and discomfort of having a smear taken as a barrier.<sup>11</sup> This may include a number of factors, such as: pain and discomfort during the procedure, male doctors being less gentle than female doctors, and the invasiveness of the procedure.

#### Not knowing what to expect

Some women are discouraged by a previous negative experience of having a smear taken, especially if they feel the procedure was not explained properly, or they did not feel fully informed.<sup>11</sup> Furthermore, if these uncertainties are shared with friends or family/whānau, this barrier can become widespread.

#### New immigrants

Some new immigrants to New Zealand will not be familiar with cervical screening if they have not previously been exposed to a cervical screening programme. Although routine cytological screening is common in wealthier countries, most developing countries lack the infrastructure and trained personnel needed to provide a programme.

Approximately 25% of new immigrants report needing assistance with the health system, which may be further complicated by one in five rating their English language ability as moderate to poor.<sup>14</sup> One study found that in women immigrants to New Zealand not previously exposed to a cervical screening programme, not knowing

where to go and not realising it is necessary, were the most frequently cited reasons for never having had a smear.<sup>15</sup>

While the values of European New Zealand women are generally aligned with New Zealand health practice, this is less likely for women with other cultural influences. Acculturation is the process of one cultural group adopting the beliefs and behaviour of another group, usually a minority group adopting habits and language patterns of the dominant group. When women have been in a country for some time and have become more acculturated, they are more likely to participate in cervical screening.

#### Cultural viewpoint of health

As a way of understanding more complex scientific and medical concepts, people may relate the information back to the things in their life they do understand.<sup>16</sup> Māori, along with many other indigenous people, often hold an overall view of health that is quite different to Western views. For example, common beliefs about cancer may include that it is contagious, it implies certain death and it may be a punishment, curse, payback or is predetermined. People may not seek treatment because they think they have the power to fight cancer through their beliefs, feelings and perceptions.

For some cultures, visits to health providers do not occur until there are symptoms. It is also commonly believed that primary prevention is achieved by the individual, through maintaining a good diet, achieving good spiritual balance and consuming herbs that promote health, rather than by attending a doctor when there are no symptoms of disease.

#### **Overcoming barriers**

Being aware of the barriers to cervical screening is not sufficient to overcome them. In addition to national initiatives (see sidebar), carefully targeted planning at a practice level is necessary to address disparities.

# National initiatives to promote cervical screening

The importance of increasing cervical screening rates is recognised by the PHO Performance Management Programme. Most PHOs have initiatives to reduce the barriers to having a smear. Many of these initiatives include free smears for Māori and Pacific women and women from areas of high deprivation, as well as women overdue for smears, free women's clinics and mobile cervical screening services.

Recently the NCSP has initiated a significant social marketing campaign/health promotion programme, to educate and encourage Māori, Pacific and Asian women in particular, to have regular cervical smears.

Although the NCSP campaign can be expected to help reduce the disparities in cervical screening rates, there will continue to be women who remain unscreened or under-screened. General practice is in a unique position to encourage all women to participate in the NCSP. The first step to increasing cervical screening rates is to invest time in becoming familiar with the needs of the local community and establishing the trust of the women being targeted.

**Target the disparities.** Currently European women are accessing cervical screening services at acceptable levels, and as a result have the lowest levels of cervical cancer and associated mortality. Resources should be targeted to the women who are not receiving cervical smears – Māori, Pacific and Asian women and women from areas of high deprivation.

Although we often refer to the "hard to reach" – it is more helpful to consider a broader range of reasons why women do not have regular cervical smears, e.g. women who are:

- Hard-to-find
- Unconvinced
- Uninformed
- Under-screened
- Undecided

Consider – are these people "hard to reach" or is your service "hard to use"?

#### Start with your practice population

Starting with your own practice population here are some practical steps:

- Perform a computer search to identify the women in your practice who have never had a smear or who are overdue for cervical smears
- Contact the National Cervical Screening Programme (0800 729 729) to check if smear has been performed by another smear taker, and to check screening histories and recall, if necessary
- Place an alert on a medical record, so the issue can be discussed when the patient next attends.
- Invite all women who are overdue by letter or telephone to participate
- Think of approaches relevant to your practice population

#### Invest time in building relationships and trust

"It comes down to the basics. Taking time to talk to women, listening to their concerns, respecting their wishes and building trust. It can take some women a long time to be ready, but it is important to keep building that relationship." – Māori/Pacific Health Nurse

It may take several consultations for some women to feel comfortable about having a smear. Depending on their own personal experiences, some women may never be ready. It is important to acknowledge concerns and fears and provide clear information about the procedure.

## Mā te rongo, ka mohio; Mā te mohio, ka mārama; Mā te mārama, ka mātau; Mā te Mātau, ka ora

Through listening comes awareness, Through awareness comes understanding, Through understanding comes knowledge, Through knowledge comes life and well-being.

#### Make it a positive experience

Emphasise how cervical screening benefits both the patient and their family/whānau. Validate their decision to participate and encourage them to encourage others. It is also important that women are made to feel as comfortable as possible about the process. Women who have had a positive experience are more likely to return.

#### Ensure women feel prepared

It is important to take the time to ensure the woman is well prepared, relaxed and comfortable prior to the collection of the cervical smear. Important things to consider are:

- Don't rush the woman, if she's not ready this time, talk to her in preparation for the next time
- Encourage her to ask questions to gauge her understanding of the information you are sharing
- Reduce her discomfort by giving her time to absorb the information

- Ask her if she would like to see the speculum. Allow her to hold it if she chooses, and explain how it will be used
- Let her know she can have a support person
- Tell her to let you know if she is uncomfortable during the procedure

#### Make it less embarrassing

Give women a choice of smear taker and ensure they know the process is confidential. This may be difficult if they know someone in the practice, especially if they are worried that aspects of their sexuality may be revealed.

It is important to take practical steps to reduce embarrassment or vulnerability while the smear is being collected. This may include:

- Being covered while lying on the bed
- Pulling curtains around the bed
- Ensuring the environment is relaxed (e.g. pictures, warm room, music)
- Offering different positions to lie in
- Offering disposable plastic speculums
- Warming the speculum

#### Provide culturally appropriate smear takers

Some Māori and Pacific health providers have smear takers and may provide a free or low cost service. Cervical Screening health promoters, specialising in the promotion of screening to Māori, Pacific and Asian women, are also available in most areas (contact your DHB) and will be able to assist practices in ensuring their services are culturally appropriate. It may be worth exploring what options for smear taker training are available in your area. Depending on availability, nurse smear taker training is free.

Language difficulties are a major barrier for many Asian and some Pacific and Māori women, therefore it is important to provide access to a smear taker with appropriate language skills where possible, otherwise the use of an interpreter is encouraged. Many PHOs are clients of Language Line, a telephone interpreting service managed by the Office of Ethnic Affairs. If the service is available through the PHO, an interpreter can be available via the telephone almost immediately. There are 40 different languages available with a choice of gender of the interpreter.

#### **Communicating results**

Reassure patients that an abnormal cervical smear result rarely indicates cancer but rather screening provides the opportunity to detect early changes and if necessary, treatment can be initiated.

Ask patients about their preferred method of receiving results. They may wish that even normal results are communicated to them. Make sure the patient knows when their next smear is due and place a recall on your PMS.

Tell the patient that they may be asked to return for a repeat test if the smear is reported as unsatisfactory. The

rate of unsatisfactory smears is likely to be less with the advent of liquid based cytology.

#### **Cost solutions**

In recognition of cost being a major barrier for many women, most PHOs have initiatives in place to provide free or low cost cervical screening, for targeted populations.

Māori/Pacific providers, family planning clinics and practice nurses may offer a low cost or free alternative. Become familiar with the services available in your area and ensure the patients who would benefit most have access to these services.

Competencies for Smear Taker Training is a new document available.<sup>17</sup> This has been developed by the NCSP in consultation with stakeholders and replaces the NCSP Training Standards for Smear Takers 2002. It is available from **www.nsu.govt.nz** 

### September is Cervical Screening Awareness Month

The NCSP is promoting September as "Cervical Screening Awareness Month".<sup>18</sup> This is a national initiative, supported by the New Zealand Cancer Society and the Family Planning Association. There will be an increased awareness of the cervical screening programme, providing the opportunity for local promotional activities, supported by national advertising and promotions.

The aim is to get women talking about the benefits of cervical screening, and to encourage the women around them to have a cervical smear. All clinics and smear-taking practices throughout New Zealand have been provided with promotional resources for the month, including:

- Awareness Month posters for display in practices during September
- Free 30 mL hand and body lotion samples for distribution to women who have their smear test during September (while stocks last)
- Miniature promotional stands for display on reception counters

#### Resources

For information about cervical screening in New Zealand visit: www.cervicalscreening.govt.nz

Resources are available to help inform women about cervical screening and encourage participation.

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