

# WOMEN'S health

## update

### The saga of cervical screening in New Zealand: insights for the future

By Charlotte Paul, Emeritus Professor, University of Otago

**Cancer screening initiatives have always had to steer a difficult course as they attempt to maximize benefits and minimise harms to people. The goals of cancer screening are to reduce morbidity and mortality from the cancer in question and to minimise harms arising from detection and treatment. To this end, the goals have recently been described as: to increase the detection of consequential disease – which is more likely to lead to spread, metastasis and death – while minimising the discovery of indolent lesions which will not progress or threaten life.<sup>1</sup>**

In the US, screening for cervical and bowel cancer has led to substantially decreased mortality through the removal of slow growing but consequential lesions. These two screening initiatives have also led to substantial falls in incidence because consequential pre-cancerous lesions have been identified and treated before cancer occurs. For bowel cancer, in the US but not in New Zealand, this is by primary colonoscopy and the removal of adenomatous polyps.

For some other cancers, e.g. breast and prostate, both indolent and consequential tumours are identified by screening. For still others, e.g. thyroid cancer, screening appears to detect mainly indolent tumours. For all these cancers over-diagnosis and over-treatment are potential problems.

For cervical cancer in New Zealand, since 1990, incidence has fallen by around 50 per cent and mortality by around 60 per cent. Of particular note, as shown in Figure 1, Māori incidence has fallen more steeply, and both relative and absolute differences with non-Māori have narrowed. Pacific incidence has also fallen, while Asian incidence has not.<sup>2</sup> It may be that Māori and Pacific providers have helped increase the uptake of cervical screening amongst these women.

Whether cancer screening is going to provide benefit and cause little harm depends on the test, the treatment, the epidemiology and biology of the disease, and the health system response.

#### The dynamic epidemiology of cervical cancer

Cervical cancer incidence was falling in many countries before screening began, or falling in some groups and rising in others. The first person in New Zealand to report that incidence and mortality were increasing among young women (while decreasing among older women) was gynaecologist Herbert Green at National Women's Hospital (NWH) in 1981.<sup>3</sup> Green concluded (wrongly) that because the number of smear tests had increased steeply over the same time, cervical screening was ineffective.

In 1986 Cox and Skegg showed that the increase in incidence and mortality among younger women was explained by a striking birth cohort effect. Women born in the 1940s and 1950s had a greatly increased risk compared to those born earlier.<sup>4</sup> They concluded that this in turn might be largely due to more liberal sexual behaviour from the 1960s (and by implication increasing

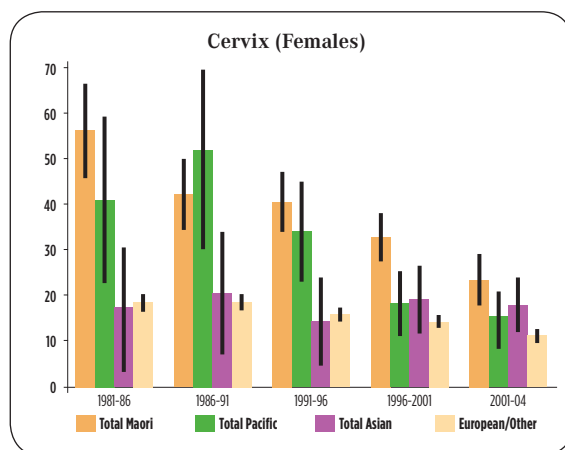


Figure 1. NZ Incidence rates of cervical cancer by ethnic group. Age standardised to WHO World standard population. Blakely et al. 2012.

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spread of what we now know as the necessary cause of cervical cancer, Human Papilloma Virus (HPV)). They estimated that screening might have prevented 25 per cent of then current incidence. A major epidemic of cervical cancer could be expected as these women aged, and took their higher risk into older ages with greater underlying incidence, unless screening was much improved.

Their projections for 2004-2008 were for 440 cases and 148 deaths, in the absence of improved screening.<sup>5</sup> The actual average incidence and mortality in those years was 160 and 60 respectively.<sup>6</sup> Hence cervical screening is saving the lives of at least 88 women per year, and (because the population has grown faster than predicted), more likely 100 women a year.

This dynamic epidemic is continuing. In England and Wales, 1990 to 2010, there has been an increase in incidence among women aged 20-29 years. Once again, a further change in sexual behaviour and hence HPV transmission has been implicated.<sup>7</sup> In New Zealand we have not had an appreciable increase in incidence in the youngest

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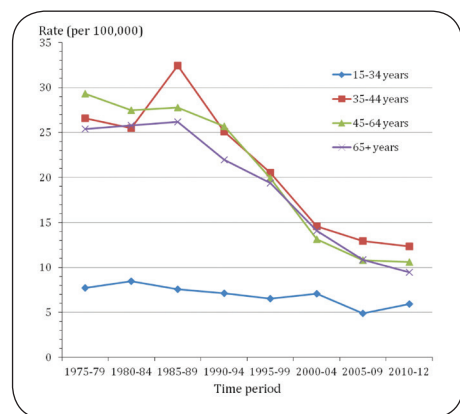


Figure 2. Age specific incidence rates of cervical cancer, 1975 to 2012

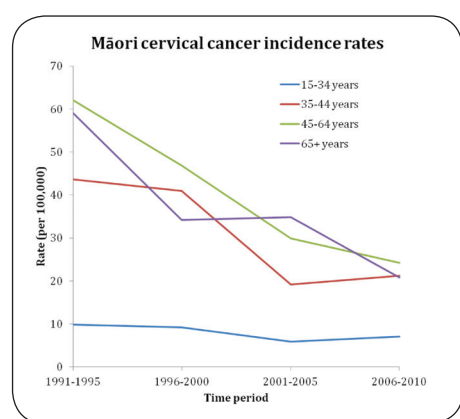


Figure 3. Māori age-specific incidence rates of cervical cancer, 1991 to 2010

age group. Figure 2 shows age specific rates over time; there was an increase in the 1970s/ early 1980s in younger age groups as previously described but then a decline, attributable to screening, across all age groups. Figure 3 shows age specific incidence rates among Māori and shows that the greatest decline has been amongst older women.

### Over-treatment and under-treatment

The lesions screening aims to detect are consequential, not indolent. Ideal for screening are slow growing *and* consequential lesions.<sup>8</sup> If we treat indolent lesions, that is over-treatment; if we don't treat the consequential ones, that is under-treatment.

Even for cervical screening, some lesions detected are indolent and some are consequential. For instance, certain low-grade lesions will usually regress and should initially be observed, not treated.<sup>9</sup> On the other hand, Green, against evidence that carcinoma in situ (CIS) was consequential, decided it was indolent, and gained approval of NWH authorities not to treat women with this condition. Instead he relied on repeat smears and repeat incomplete biopsies (punch, wedge, or ring) to check for invasive cancer. The women's experience was documented by Judge Cartwright,<sup>10</sup> and

again in a re-examination led by Margaret McCredie.<sup>11</sup> Women who received only a punch or wedge biopsy had 10 times the incidence of cervical cancer compared to women who received a cone biopsy or hysterectomy, and almost all the deaths were in the former group.

Hence the main problem in New Zealand has been under-treatment. Nevertheless, there will still be some women treated, even with CIS, who would not develop invasive disease in their life-time if left untreated (up to 50 per cent of such women will develop invasive cancer by 30 years).<sup>12</sup> Over-treatment is of special concern when the potential harms and costs of treatment are high. For cervical pre-cancers, the harms and costs of treatment are generally less than, for instance, for indolent prostate cancers, but are still important to minimise.

### Over-diagnosis and under-diagnosis

Over-diagnosis remains a problem in New Zealand; for instance when lesions are detected that would regress before the next screen. Currently, a third of women have smears 2 yearly or more often (instead of the recommended 3 yearly). Similarly 15,000 women a year are being screened under age 20 (the recommended age for starting screening). Yet again, in New Zealand, the most obvious failing has been under-diagnosis, through mis-reading of cervical smears. The ministerial inquiry into this problem in 2001 concluded that there had been an unacceptable level of under-reporting of high grade smear abnormalities in the Gisborne region, and problems in other regions could not be excluded.<sup>13</sup> The outcomes of the inquiry were compulsory performance standards, quality assurance standards, and monitoring of the programme.

### Health service response: an organised cervical screening programme

Cervical screening started in New Zealand in the mid 1950s at NWH. There were a series of demonstration projects around the country, but attempts to set up a national register foundered in the late 1960s. This has again been attributed to the influence of Green and NWH. No national recommendations were made until 1985.<sup>14</sup>

There were signs of resistance to these recommendations. After the release of the 'Skegg Report' a national meeting was convened. The medical superintendent of NWH reported that there were two camps at the hospital. One camp opposed screening because: screening programmes were successful only in countries where there were health registers and a population-wide basis for looking for the condition; there was no epidemic of cervical cancer, and it was a relatively uncommon cancer in New Zealand; quality of smears was not always adequate; quality control of cytology was inadequate;

and screening programmes do not get at the 'high risk' groups.<sup>15</sup>

These comments showed a surprising fatalism about the health service's ability to improve. Judge Cartwright took up these matters two years later. In contrast to this fatalism, she noted the impediments and recommended ways to overcome them (her recommendations coming partly from the Ministry of Women's Affairs which had consulted widely with women around the country). It took another 5 years, until 1993, for a screening programme close to the sort envisaged by Judge Cartwright to be put in place. Indeed all the parts were not in place until well after the Gisborne Inquiry.

### Comments for the future

Screening is an intermediate technology; it is complex and resource intensive. It is at present *essential*, but primary prevention with HPV vaccination is now possible. It is of concern that uptake among 12 year olds is only 50 per cent, and the essential linkage between the immunisation register and the screening register has not occurred.

Effective cancer screening requires huge dedication. Although we have a successful programme, there are still unaddressed problems. The latest audit is still incomplete (from 2009) and there is still no population-based register in use for any cancer screening programmes in New Zealand.

Fatalism can stand in the way of complex public health action. We are right to be cautious in developing new screening programmes, but we have been too fatalistic. In a similar way to those people at NWH in the 1980s, expert advice on bowel cancer screening is not encouraging.<sup>16</sup> Beat Bowel Cancer Aotearoa will remind you that in New Zealand 100 people die every *month* from bowel cancer, and though some are elderly, many are of middle age. Good health services require realistic faith in the possibility of improvements, not fatalism.

Judicial inquiries provide a motivating force for action. Both the Cartwright Inquiry and the Gisborne Inquiry provided the factual insights and the legal and moral force to overcome barriers and propel action. An organised programme, with intense community support, came out of the Cartwright Inquiry. Laboratory standards and new ethical standards to enable audit came out of Gisborne. Both have contributed to saving the lives of 100 women every year.

**Acknowledgements:** This paper is based on an address given at the Cartwright Legacy Conference in 2013. The author thanks Dr Hazel Lewis, National Screening Unit, and Associate Professor Brian Cox, Preventive and Social Medicine, University of Otago for additional information.

\* *References for this article can be found online: <http://www.womens-health.org.nz/side-menu/news-2.html>*

# Big Latch On, Big Gains

By Isis McKay

**When Women's Health Action first started the Big Latch On in 2005, we never dreamt it would be the international success that it now is. Last year 14,536 babies took part in the Big Latch On across 28 countries.**

To celebrate the 10th year of the Big Latch On, Women's Health Action is delighted to announce the launch of the 'I latched on' breastfeeding 'selfie' campaign.

The selfie initiative has been created to provide breastfeeding women who cannot attend a Big Latch On event a chance to participate online and encourage them to connect with other breastfeeding women via social media sites such as Facebook.

Recent New Zealand based research has shown that breastfeeding women who are connected to online communities report feeling more confident and supported.<sup>1</sup> Using the internet to support breastfeeding is a relatively novel method of health intervention in an area which has traditionally always used face-to-face techniques. International research is showing that social media is an appropriate strategy for increasing breastfeeding duration and that breastfeeding campaigns that are innovative in their approach and use technology may be more effective in changing breastfeeding behavior.<sup>2</sup>

The other exciting announcement is that this year the Big Latch On will take place over two days - Friday the 1st and Saturday the 2nd of August. This decision was made to encourage more working mums and breastfeeding supporters, such as partners and family, to attend the Big Latch On events. Attendance of support people is particularly important as research shows that a significant barrier to breastfeeding is lack of peer support from family and friends.<sup>3</sup> Also, women with no prior exposure to breastfeeding in their family or social network, who feel that their choice to breastfeed makes



them different to other women in their social circle, are more likely to prematurely cease breastfeeding.<sup>4</sup>

Anyone can host a Big Latch On venue and your venue can be anywhere such as a church, local marae, your home, cinema, workplaces, hospital, a local café, play centre - we have even had a Big Latch On on a plane. Anywhere as long as it is in New Zealand.

For more information please visit [www.biglatchon.org.nz](http://www.biglatchon.org.nz) or contact Isis McKay on 09 520 5295 or [breastfeeding@womens-health.org.nz](mailto:breastfeeding@womens-health.org.nz).

\* *References for this article can be found online: <http://www.womens-health.org.nz/side-menu/news-2.html>*

# Gender bias in medical research: Cultivating Health Inequalities

By Maggie Behrend

**In early 2014, the Mary Horrigan Connors Center for Women's Health and Gender Biology at Brigham and Women's Hospital released a report called 'Sex-Specific Medical Research: Why Women's Health Can't Wait'.<sup>1</sup> The report argued that greater representation of women in medical research and gender analysis is needed to improve the health and wellbeing of women, and ensure gender equality in health care.**

In the US, efforts to increase women's involvement in clinical trials have been formalised since the 1993 National Institutes of Health (NIH) Revitalization Act, which required NIH funded clinical trials to include women and minorities. A number of other US agencies, including the FDA, followed suit and introduced similar policies.<sup>2</sup>

However, more than twenty years on, gender bias continues to persist at every stage of research. This is concerning as men and women have different experiences of disease,<sup>3</sup> owing to biological and social factors.

Ischemic heart disease, for example, is the second leading cause of death among New Zealand women after cancer.<sup>4</sup> Women are more likely than men to live in poverty,

impacting their lifestyles, and they are also more likely to suffer from depression and anxiety, all of which are risk factors for coronary artery disease. There are risks associated with pregnancy, and diabetic women are at a greater risk of heart disease than diabetic men.<sup>5</sup> Sex differences are also evident in the symptoms and progression of ischemic heart disease, and response to treatment.<sup>6</sup>

Despite this, much of the international research about coronary artery disease does not adequately integrate sex or gender into their studies. In European cardiovascular disease trials conducted between 2006 and 2010, women made up one third of participants, significantly less than the population's burden of disease. Further, only half of trials included a gender analysis of the results.<sup>7</sup> The US has similar participation rates of women, but only a quarter to one third of mixed-sex NIH-sponsored trials reported results according to sex.<sup>8</sup>

Even before human trials commence, the significance of sex is discounted. In the early phases, scientists often fail to design research which considers sex, and many animal trials

only use males or do not report the sex of animals.<sup>9</sup> More could also be done at the implementation and evaluation stages to ensure learnings from research about sex differences are better incorporated into health care practice and the effect on health and wellbeing is measured.

As the Mary Horrigan Connors Center report states: "Medical research that is either sex- or gender-neutral or skewed to male physiology puts women at risk for missed opportunities for prevention, incorrect diagnoses, misinformed treatments, sickness, and even death."<sup>10</sup>

The evidence of this report provides support to Women's Health Action's call for a National Women's Health Strategy in Aotearoa New Zealand. Without a focus on the effects of gender and sex in research, policy and health service practices, health equality will not be realised and medicine will be doing a disservice to women.

The full Mary Horrigan Connors Center for Women's Health and Gender Biology at Brigham and Women's Hospital report can be accessed here: [http://www.brighamandwomens.org/Departments\\_and\\_Services/womenshealth/ConnorsCenter/Policy/ConnorsReportFINAL.pdf](http://www.brighamandwomens.org/Departments_and_Services/womenshealth/ConnorsCenter/Policy/ConnorsReportFINAL.pdf)

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# Putting Gender Back on the Health Agenda

By Sandy Hall

**Policy Analyst, Dr Sandy Hall, discusses the motivation for Women's Health Action's recent publication, 'A Case for a National Women's Health Strategy in Aotearoa New Zealand', which makes a compelling case for developing a specific health strategy for women and the principles that should guide it.**

The World Health Organization's definition of health includes "complete physical, mental and social wellbeing and not merely the absence of disease and infirmity. Women's Health involves their emotional, social and physical wellbeing and is determined by the social, political and economic context of their lives, as well as biology".<sup>1</sup>

In a 2001 article for Women's Health Update<sup>2</sup> Sandra Coney criticised the lack of a gender focus in health. She argued that in the late 1980s, an infrastructure of women's health advisors, policy-makers and planners existed within the health sector. This included a Women's Health Committee, women's health manager and a section in the then Department of Health, and a Women's Health Committee in the Health Research Council.

By 2001, however, Aotearoa New Zealand was lagging behind other countries that included gender as part of a global focus on the determinants of health and that this "neglect mirrors the disappearance of a women's health focus in the New Zealand health sector". Coney noted this regression was underpinned by a number of factors including a political belief that policy should be gender neutral, and an increasing focus on disease and lifestyle factors which might cause future disease. Adding to this was

a focus on female 'mortality advantages', which ignored the longer period of life women live in a dependent state.<sup>3</sup>

Since Sandra Coney's article, there has been over a decade of support for a gender focus in health, yet New Zealand has never had a women's health strategy. Similar jurisdictions to Aotearoa New Zealand, such as Australia, Canada and the USA as well as many developing countries have specific women's health policies or strategies which aim to address health inequalities and the social determinants of health, as well as the diversity of their female populations.

Women's Health Action began to investigate strategies developed in countries similar New Zealand, such as Australia and Canada, along with health statistics and studies and previous proposed strategies from Aotearoa New Zealand. We then developed a discussion document examining why we need a women's health strategy, what it might consist of, and which issues have already been identified as important to improving women's health.

After reviewing the evidence, Women's Health Action continues to believe it is essential that health researchers, policy makers and health care providers address health issues unique to, prevalent amongst or more serious in women, and illnesses which have differing risk factors for women and girls.<sup>4</sup> We believe it is time that Aotearoa New Zealand develops a specific women's health strategy that is consistent with the Treaty of Waitangi, other national legislation such as the Human Rights Act, and the international conventions to which

we are signatories.

The discussion document highlights the key issues of violence, reproductive health, socioeconomic disparities, health equity between women and the health issues of specific populations including Māori, Pacific, older, teen, disabled, rural and LGBTI women, with a focus on prevention and promotion and a life course approach. It emphasises recognising gender as a basic determinant of health, and a focus on gender equality, establishing a reliable evidence base, a life course approach, developing health sector capacity and representation, and ensuring women's health issues are reflected across government sectors.

Women are the majority of health consumers, health service providers and carers in our society. Improving the health of women improves the health of the whole community. We require a health system that is responsive to the needs of all women and the provision of "appropriate gender sensitive care". As Coney noted in 2001, "Women have more distinct stages in their lives...We should not over-emphasise biology, to the exclusion of other determinants of women's health, but we need to keep in mind the relationship between biology and social and economic participation in women's lives".

Read A Case for a National Women's Health Strategy in Aotearoa New Zealand here: <http://bit.ly/1paSkpV>

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## NOTICEBOARD

### WORLD ELDER ABUSE AWARENESS DAY

15 JUNE, EVENTS AROUND NZ

Events around the country being organised by Local Age Concerns.

[www.ageconcern.org.nz/safety/elder-abuse/world-elder-abuse-awareness-day-events](http://www.ageconcern.org.nz/safety/elder-abuse/world-elder-abuse-awareness-day-events)

### ANNUAL CONFERENCE OF THE PERINATAL AND MATERNAL MORTALITY REVIEW COMMITTEE

17-18 JUNE - WELLINGTON

Come along and learn about the latest perinatal and maternal mortality and morbidity data and its implications for improving the quality and safety of care for New Zealand's mothers and babies.

[www.hqsc.govt.nz/news-and-events/event/1201/](http://www.hqsc.govt.nz/news-and-events/event/1201/)

### SYMPOSIUM ON WOMEN AND CHILDREN

4 JULY - AUCKLAND

A 'State of the Nation' discussion on how life is for Women and Children in New Zealand in 2014.

[womensrefuge.org.nz/WR/Events/Symposium%20on%20Women%20and%20Children.htm](http://womensrefuge.org.nz/WR/Events/Symposium%20on%20Women%20and%20Children.htm)

### UNICEF NEW ZEALAND YOUTH CONGRESS

11-13 JULY - CHRISTCHURCH

UNICEF NZ is offering 50 young New Zealanders the chance to learn more about the world, share ideas about how to make a difference and gain the skills needed to take action for children.

[www.unicef.org.nz/YouthCongress](http://www.unicef.org.nz/YouthCongress)

### WOMEN'S REFUGE APPEAL WEEK

14 - 20 JULY

<https://womensrefuge.org.nz/>

### HE TAI PARI

14 - 15 JULY - WELLINGTON

The conference focus is on understanding how providers working with vulnerable children and young people and their whānau can shift to an outcomes focus.

<http://hetaipari.co.nz/>

### NOURISH WORKSHOPS

9 JULY - HAMILTON, 10 JULY - AUCKLAND  
Nourish is designed for those who work with young people and want to support positive

body image, address appearance-based bullying and promote body diversity. It offers a smorgasbord of training ideas to promote body confidence, self-esteem and critical thinking for young people.

Email [rebecca@womens-health.org.nz](mailto:rebecca@womens-health.org.nz)

### CARTWRIGHT ANNIVERSARY SEMINAR

24 JULY, AUCKLAND

Women's Health Action's organises an annual seminar to commemorate the release of the Cartwright Inquiry Report in 1988. This year's topic is elder abuse and focuses on the particular issues women face.

Email [info@womens-health.org.nz](mailto:info@womens-health.org.nz)

### THRIVE TEEN PARENT SUPPORT CONFERENCE

24-25 SEPTEMBER - AUCKLAND

The conference will explore ways in which programmes, community based initiatives, policy and research enables teen mums and teen dads to build, follow and fulfil their dreams.

[www.thrive.org.nz/teen-parent-support-conference-2014-0](http://www.thrive.org.nz/teen-parent-support-conference-2014-0)



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Women's health information - [www.womens-health.org.nz](http://www.womens-health.org.nz)

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