

# Cancer Connections

WELCOME to the Spring edition of **CANCER CONNECTIONS**, a quarterly newsletter keeping you in touch with the work of the national Cancer Control Programme.

SPRING 2009

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# Cancer work plan sets fresh priorities

Improving treatment and overall survival for people with lung cancer and bowel cancer is one of the top priorities for the national Cancer Control Programme in the coming year.

These two cancers have been singled out for special attention in the sector's Cancer Control Programme work plan for the 2009/10 year.

The Cancer Control Programme is a national work programme that covers Ministry of Health, District Health Boards, and regional cancer networks activity to implement the Government's priorities for cancer and the New Zealand Cancer Control Strategy.

National Programme Manager for Cancer, Deborah Woodley says she is really pleased that for the first time there is real alignment of work priorities across the cancer sector.

The work plan was set in consultation with District Health Boards and regional cancer networks. For a copy of the work programme, go to: <http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-strategyandactionplan#programme>

Lung cancer and bowel cancer have been identified as two cancers where New Zealand can make significant improvements in the treatment received by patients, and in our overall outcomes.

National Clinical Director for the Cancer Programme, Dr John Childs believes there is a significant opportunity to improve quality of care, and this should lead to improved survival rates.

New Zealand's five year survival rate for lung cancer is about 10 percent, well below that of many OECD countries where rates of 15 percent to 17 percent are reported. For Māori, the five year survival rate for lung cancer is 5 percent, half the national average.

Dr Childs says "We should be able to do better."

The five year survival rates for bowel cancer are 60 percent, which is comparable to other OECD countries. However the incidence, the advanced stage of the disease at diagnosis and the high death rate mean further improvements are needed.

Specific initiatives for these two priority cancers are happening at national, regional and local levels.

At a national level, planning is underway for a future bowel cancer screening programme. This is being developed by the Ministry's new Bowel Cancer Team, led by Mhairi Porteous (Programme Manager) and Dr Carol Atmore (Clinical Director).

The Ministry is also facilitating a national lung cancer meeting on 6 November to initiate a national work programme on the establishment of a national lung cancer working group to develop standards and protocols for treatment.

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John Childs  
National Clinical Director

## Cancer work plan sets fresh priorities continued..

Dr Childs says the Ministry greatly appreciates the clinical leadership and support provided on this initiative by Dr Charles de Groot, Clinical Director for the Midland Cancer Network and his colleagues in the regional cancer networks.

All four Regional Cancer Networks are undertaking regional projects on lung and bowel cancer this year. This work will both support the national work and lead to recommendations to each of the four networks' DHBs to enable them to support improvements in the quality of services provided for patients.

Ministry of Health  
National Programme  
Manager for Cancer,  
Deborah Woodley



## Expert advice from programme Advisory Groups

Three key advisory groups currently exist to provide clinical and expert advice to inform the work of the Cancer Control Programme and the palliative care work programme.

The advisory groups are either time-limited (providing advice for specific projects) or a standing group, where the role and membership is regularly reviewed to ensure ongoing relevance to the Programme. All advisory groups have agreed terms of reference.

The configuration of these advisory groups is expected to change over time to reflect changing priorities.

The current advisory groups to the Programme are listed below. The advisory groups have also established specialist work groups. In addition to these work groups the Programme links to the Paediatric Oncology Steering Group.

Advisory Group	Work Groups	Work Group Chair
Cancer Treatment Advisory Group Chair: Dr Garry Forgeson	Adolescent and Young Adults	Dr Rob Corbett
	Haematology	Dr Tim Hawkins
	Medical Oncology	Dr Andy Simpson
	Radiation Oncology	Dr Graham Stevens
Palliative Care Advisory Group Chair: Barry Keane	Specialist Palliative Care Service Specification	Dr Jonathan Adler
	Palliative Medications	Jane Vella-Brincat
	Syringe Driver	Jackie Robinson
Cancer and Palliative Care Information Advisory Group Chair: Prof Tony Blakely	Cancer Data Definitions	MoH contact: Kirstin Pereira
	Palliative Care Data Definitions	Dr Warrick Jones

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# Modern makeover for cervical cancer screening

Cervical screening in New Zealand is taking a giant step forward with the introduction of a new, more sensitive test that will improve the screening pathway for women.

From 1 October, human papillomavirus (HPV) testing will be included in the National Cervical Screening Programme (NCSP), providing more accuracy and less frequent screening for a range of women who return abnormal cervical smear test results.

Women having a conventional Papanicolaou (Pap) smear test will also be tested for HPV if they:

- are 30 years and over, with low grade cell changes
- have been treated for a high grade lesion
- have had a colposcopy which has shown unusual results.

Dr Hazel Lewis, Clinical Leader of the National Screening Programme says HPV testing will modernise the highly successful cervical screening programme and reflect international evidence and practice.

“The Pap test we use is about 50 years old and although it has served all screening programmes internationally very well, it has its limitations,” she says. “Its sensitivity and its ability to detect abnormalities is limited. About 20 percent of cases can be missed.”

Dr Lewis says HPV is now known to be the cause of almost all cervical cancer. The HPV test will clearly determine which women need to be referred on for colposcopy.

The HPV test will also allow better monitoring of women who have



Dr Hazel Lewis

been treated through colposcopy. These women have required an annual smear until they are aged at least 70. Use of the HPV test will allow these women to return to three yearly screening if they return negative HPV results over two years.

The NCSP was set up in 1990 with the aim of reducing the incidence of cervical cancer in New Zealand, and the number of women who die from it. By 2008, the programme had achieved a 50 percent reduction in cervical cancer cases and a 60 percent reduction in deaths from the disease.

Recent modelling work done by the Cancer Council of New South Wales for the NCSP suggested about 760 invasive cervical cancers would occur annually

in New Zealand in the absence of screening, rather than around 160 currently reported to the New Zealand Cancer Registry

“The programme has been so successful,” says Dr Lewis. “We are among the top five countries in the world in terms of cervical screening coverage. The HPV testing is a major modernisation and is necessary if cervical screening is to continue to perform effectively and efficiently in the new era of HPV vaccination.”

Further information on the NCSP, including fact sheets for smear takers and women are available on [www.cervicalscreening.govt.nz](http://www.cervicalscreening.govt.nz)

# E-Learning tool gets great reception

Delivering training to busy health professionals can be difficult.

When the Ministry of Health tobacco control team sought to equip New Zealand's approximately 70,000 registered health professionals with basic information about smoking cessation, it was time to talk to health professionals and develop something people could complete at their desks.

The strategic direction for tobacco control in New Zealand involves the ABC approach:

A - **ASK** about smoking status.

B - Give **Brief** advice to stop smoking to all people who smoke.

C - Provide evidence-based **Cessation** support for those who express a desire to stop smoking.

All health care workers, regardless of their location, specialty or seniority, have a responsibility to help people who want to stop smoking.

The E-learning tool was designed by the learning design company Wavelength and launched at the Goodfellow Symposium, in Auckland, at the end of March.

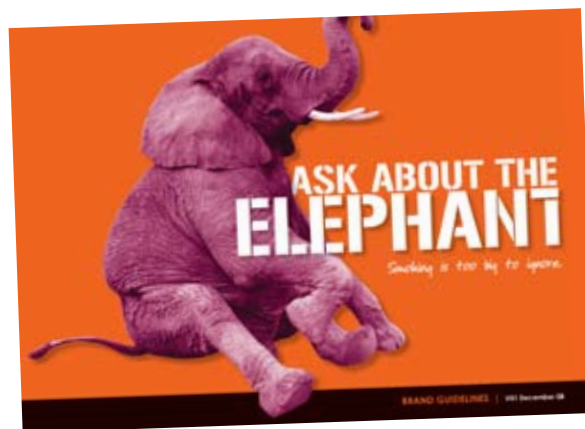
It features an image of a large pink elephant, developed to be used with health professional audiences to show 'Smoking is too big to ignore', and the importance of 'Asking about the elephant'

The tool takes 20 - 45 minutes to complete and enables registered health professionals to learn about the ABC approach and to become Quit Card providers. Quit Card providers can fill out a card for a person who wants to quit smoking, so that person can get subsidised Nicotine Replacement Therapy (NRT) from a pharmacy.

The E-learning tool training is endorsed by the Royal New Zealand College of General practitioners, for CME points. Health professionals who complete the module are provided with a printable certificate as evidence of professional development. The E-learning tool also provides useful training for anyone wanting basic information about smoking cessation.

Since its launch more than 2000 people have completed the training. The response has been resoundingly positive with comments like: "It feels right, it is comprehensive, it is thoughtful, it is helpful, it is encouraging and it is simple" (PHO CEO). There has also been overseas interest in adapting it for other audiences.

The tool is well worth a look at [www.smokingcessationabc.org.nz](http://www.smokingcessationabc.org.nz)



# LCP provides opportunity to get it right

The Liverpool Care Pathway is gaining support and recognition around the country as a valuable evidence-based, integrated care pathway that guides the care of patients in their last hours or days of life.

Since the Ministry of Health-funded national office opened in November 2008, interest in the Liverpool Care Pathway for the Dying Patient (LCP) has surged ahead, with the programme now adopted by 10 of the country's 21 District Health Boards (DHBs).

The LCP was developed in the United Kingdom in the 1990s as a means of transferring the hospice model of best practice care for the dying to other settings.

The pathway guides health care professionals to deliver high quality care to dying patients and their families/whanau in the last days and hours of life. It is an internationally recognised tool capable of improving the quality of care for the dying, irrespective of place of care or diagnosis. To date, 17 countries including New Zealand are working with the LCP.

The LCP prompts health care professionals to consider all possible reversible causes for the person's current condition as part of the decision to change the direction of care. The programme ensures all treatments that are of benefit to the patient are continued, including appropriate medications. It does not endorse continuous deep sedation.

National LCP Lead Theresa Mackenzie says the objective is for all DHBs to be using the programme, and significant progress towards this is expected next year.

"The LCP has generally been greeted very positively," says Theresa. "Every day we receive phone calls and emails from organisations

wanting to learn more about the programme and how to implement it in their setting."

She says care during the final stages of life should be seen as urgent.

"As health care professionals we have an obligation to ensure we have the knowledge, skills and tools to get it right for the patient and their family/whānau," says Theresa.

The greatest interest in the LCP is coming from residential care providers.

There was an 80 percent increase in the number of registered LCP sites in residential care facilities between July 2008 and March 2009.

As at September there were 135 registered LCP sites throughout the country. Of these, 16 were hospices, 12 were hospitals, 98 were residential care facilities and 9 were community settings.

Health and Disability Commissioner, Ron Paterson, has endorsed the LCP as "a valuable tool for ensuring that dying people get the holistic care they are entitled to".

Theresa Mackenzie says "In the words of the late Dame Cicely Saunders, founder of the modern hospice movement, all the careful details of the pathway (LCP) are a salute to the enduring worth of an individual life".



Theresa Mackenzie

# Understanding patient experiences key to improving services

Jenny Short has breast cancer. She says the biggest thing that she, and other women with cancer, has to grapple with is uncertainty about the future and facing fears they may never have had to face before.

“It’s a time when most women feel very vulnerable and could feel much more afraid than necessary if they don’t have faith in the treatment or believe that their medical team is doing the best for them,” says Jenny.

Jenny has been involved in the Patient Co-design of Breast Service Project at Waitemata District Health Board (DHB), providing a patient’s perspective on services.

Uncertainty. Fear. Vulnerability.

Hilary Boyd, a project manager in the DHB’s Healthcare Improvement Team, says these are not words often seen in the project plans that cross her desk.

“I have a great job working with staff in different areas of our hospitals to improve services.”

She says traditionally, service improvement projects focus on technical issues such as process analyses, clinical guidelines, data, waiting times and average length of stay.

They often involve reference groups, comprising a mix of health professionals and managers, where information is analysed, improvements suggested and implemented. Patients may be involved in the reference group or may be asked to participate at a later stage through surveys or interviews.

The longer she is in the job, the more Hilary realises that improving services involves understanding the experiences of patients, hearing

their stories and learning from them.

“Not only that, but we should also let patients help make the changes too, if that’s what they want. So that’s what we’ve been doing in the Breast Service at Waitemata DHB,” she says.

Before they began the project, the team talked to many people about the best approach, and read as much as possible on the subject.

Of particular interest was a book by Paul Bate and Glenn Robert called Bringing User Experience to Healthcare Improvement. The authors discuss their work with head and neck cancer patients at Luton and Dunstable Hospital, England.

“After a lot of talking and thinking, we started the project by learning about patients’ and staff experiences. We held workshops, mapped patient journeys and surveyed how patients felt about going to the Breast Clinic and having a mammogram,” says Hilary.

Patients’ ‘moments of truth’ (or ‘touch points’ as Bate and Robert call them), – the times that really influenced their interactions with the hospital – were identified.

They found it’s often the little things that count.

“Patients told us that a warm, friendly smile from the receptionist can make all the difference. Being told how long they are likely to wait, who they will be seeing and what will happen next are important. Good descriptions of pain are also key. As one patient put it, the pain was more like a hornet’s nest than a bee sting.

“Patients identified the hospital gowns used for mammograms as problematic. Some didn’t like breast surgery being called elective surgery; after all it isn’t like they really had a choice.”

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# Understanding patient experiences key to improving services

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Slowly, patients and staff together have begun making changes.

For a start, gowns worn during a mammogram have been redesigned and are now being trialled at North Shore Hospital and Waitakere BreastScreen. The gowns were designed by Unitec students in a collaborative project involving staff, patients and the Centre of Compassion.

There are other things happening too. A patient-held record, which enables patients to track their appointments through their journey, has been developed and will be trialled with breast patients shortly.

Hilary says "We will also begin work soon on a DVD for patients and looking at ways patients can share their stories - through photo storyboards, for example."

As a patient, Jenny Short says she has enjoyed being part of the project. But if there was one thing she could change in the hospital, it would be to introduce a process for asking nurses and specialists questions in between appointments.

"For all those things that rush into your head after you've left the hospital, no matter how small," she says. "I think it's vital that the elements of doubt that can be eliminated by simple answers are eliminated. Women are much happier and therefore 'heal' better if they feel they're in control."

Staff are positive too. Cynthia O'Connor, Mammography team leader, says it's good to discuss things with patients and "...in this way hear of issues of discomfort or unhappiness they may have experienced. This will help to open up areas that we can possibly correct."

The four new mammography gowns being trialled at North Shore Hospital and Waitakere BreastScreen were chosen from eight prototypes designed by second year students from Unitec's Product Design Degree course.

They were showcased at a gala event on Auckland's North Shore. Working with patients and Waitemata DHB staff, the students identified the shortcomings of existing mammography gowns and came up with more user-friendly alternatives that were stylish, practical and modest.

The students considered issues such as warmth, comfort, fit, ease of medical access, suitability for mobility impaired patients and how easy they are to take on and off.



**EIGHT GOWNS:** Unitec students, with help from patients and staff, designed these eight gowns, four of which are being trialled.

# More women opt for 12 month Herceptin treatment

The number of women receiving a 12 month course of Herceptin for early HER2 positive breast cancer has been steadily increasing since Government funding for the therapy began in December 2008.

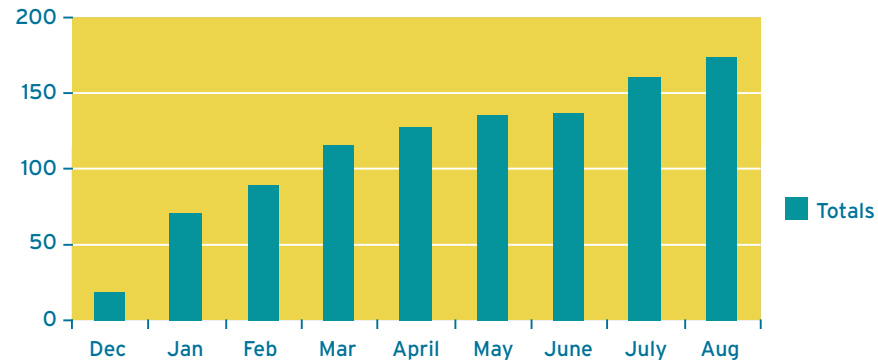
The commitment to fund a 12 month Herceptin course was part of the Government's 100 day post election action plan.

More women are now receiving the 12 month treatment course than the 9 week course, which was previously the only funded option for treatment of early HER2 positive breast cancer.

The Ministry of Health expects that up to 300 women a year will benefit from the 12 month course. As at the end of August, 174 women were on a 12 month course and 42 women were on a 9-week course.

The risks and benefits of having 12 months Herceptin treatment are different for every patient. Women are encouraged to discuss with their specialist which treatment option is best for them.

12 month Herceptin monthly treatment volumes



# Hospices feel benefit of extra funding

Hospices around the country are celebrating as they begin to feel the positive impact of extra Government funding allocated in this year's Budget.

The Government boosted hospice care funding by \$60 million over four years, increasing the proportion of average hospice funding to 70 per cent. Payments have been made to District Health Boards from 1 July 2009.

## Hospice Facts

In 2008:

- More than 13,000 people received care and support from hospices
- Hospice staff made 126,000 visits to people in their own homes
- Over 7000 volunteers gave more than 455,000 hours to hospice

access to care and support for patients, families / whanau regardless of the care setting.

"This initiative has strengthened the excellent working relationship between the Ministry and Hospice New Zealand," says Deborah. "We look forward to continuing to work together in the future."

The remaining 30 percent of hospice costs are met through fundraising and donations.

The Ministry of Health National Programme Manager for Cancer, Deborah Woodley, says the annual boost of \$15 million provides a significant opportunity for hospices to lead the sector in improving

Hospice New Zealand Chief Executive Mary Schumacher says the new money is a welcome boost and is a strong endorsement from Government about the value of hospice care that is provided free in communities.

"The funding came out of a joint recommendation to Government by Hospice New Zealand working alongside the Ministry, and we are delighted with the result," says Mary.

The funding was allocated to assist with funding shortfalls brought about by falling levels of fund raising, increasing demand and rising costs.

She says Hospice New Zealand is continuing to work with the Ministry to identify gaps in the provision of care, to ensure anyone who needs quality palliative can access it.



Hospice New Zealand Chief Executive Mary Schumacher

# Clear focus for new Cancer Control Council

The Cancer Control Council has been given a sharper focus, with new terms of reference and a strong new line-up of senior clinicians.

New membership of the 11 member Council, announced by Health Minister Tony Ryall last month, includes senior practitioners with leadership roles in core cancer disciplines, as well as non-government organisation representatives.

The council members are:

- Associate Professor Chris Atkinson, Chair, Medical Director Cancer Society and cancer specialist
- Mr Dalton Kelly, Deputy Chair, Chief Executive Cancer Society of NZ
- Ms Shelley Campbell, Former Chief Executive Waikato PHO
- Professor Brett Delahunt, HoD Wellington School of Medicine & Health Sciences, Dept of Pathology and Molecular Medicine
- Professor Mike Findlay, Professor of Oncology and Director of Cancer Trials New Zealand
- Professor Frank Frizelle, HoD Academic Dept of Surgery and Professor University of Canterbury, Colorectal Surgeon Canterbury DHB
- Dr Kate Grundy, Palliative Medicine Physician and Clinical Director Christchurch Hospital



Associate Professor Chris Atkinson

- Professor David Lamb, Consultant Radiation Oncologist, Capital and Coast DHB
- Dr Scott McFarlane, Paediatric Oncologist Starship Children's Hospital, Auckland DHB and Chair Paediatric Oncology Steering Group
- Mrs Catherine Smith, Clinical Nurse Specialist, Canterbury DHB
- Dr John Waldon, Researcher, Massey University School of Māori Studies

The Council is an independent body charged with providing expert advice to the Minister. It reports on New Zealand's performance in providing cancer care, including initiatives to reduce mortality and the impact of cancer, improving access to cancer services, and assessing the effectiveness of new initiatives.

Its new terms of reference focus on seven main areas: prevention, screening and early diagnosis of common cancers, diagnostic and treatment services for cancer patients, workforce requirements for cancer services, equity of access to cancer services, cancer data and information and high quality cancer research.

Council Chair Associate Professor Chris Atkinson says it is an interesting and exciting time for the new Council.

"There is a real energy amongst the Council members about the task the Minister of Health has set us. We are looking forward to providing constructive, solution-focussed advice to help improve cancer outcomes in New Zealand"

## New Cancer Research Partnership

A range of cancer research projects aimed at informing cancer policy, planning and service development will be undertaken over the next three years, thanks to a new partnership between the Ministry of Health and the Health Research Council.

The Cancer Research Partnership will be managed by a steering committee, chaired jointly by Dr John Childs, the National Clinical Director of the Cancer Programme, and Professor Alistair Woodward, Head of the School of Population Health at Auckland University. Other members are Associate Professor Bridget Robinson (University of Otago), Professor Bill Denny (University of Auckland) and Professor Dallas English (University of Melbourne).

The steering committee will set research priorities and the HRC will manage the process of requesting proposals.

Initial research projects are likely to include prostate cancer treatment outcomes, bowel cancer treatment outcomes and palliative care.

## Check out the work of the four regional cancer networks

The Northern Cancer Network encompasses the Northland DHB, Auckland DHB, Counties DHB and Waitemata DHB. Recent additions to their website include: Cancer in the Northern Region of New Zealand, Health Needs Assessment 2009 and the Northern Cancer Network Strategic Plan 2009-2014.

<http://www.northerncancernetwork.org.nz>

The Midland Cancer Network encompasses Waikato, Lakes and Bay of Plenty DHBs. Recent additions to their website include: The Midland Cancer Control Health Needs Assessment and the Midland Cancer Network Strategic Plan 2009-2014.

<http://www.midlandcancernetwork.org.nz>

The Central Cancer Network encompasses Taranaki, Whanganui, MidCentral, Hawke's Bay, Tairāwhiti, Wairarapa, Hutt Valley, Capital & Coast DHBs. A website for this network is currently under development and is expected to be live by the end of October ([www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz)). Quarterly newsletters will then be published via the website. In the interim information on the network can be found on the Cancer Control Council website.

<http://www.cancercontrolcouncil.govt.nz/centralcancernetwork>

The Southern Cancer Network encompasses Nelson/Marlborough, Canterbury, Otago, West Coast, South Canterbury and Southland. Check out their recent newsletters.

<http://www.sissal.govt.nz/SouthernCancerNetwork/schome.htm>

## **The Cancer Programme team**

Dr John Childs - National Clinical Director, Cancer Programme

Deborah Woodley - National Programme Manager

Simon Allan - Senior Clinical Advisor Palliative Care

Simon Bidwell - Senior Analyst

Andrea Bland - Administrator

Saskia Booiman - Policy Analyst Palliative Care

Steve Creed - Principal Technical Specialist

Kate Garland - Senior Analyst

Emma Hindson - Senior Analyst

Debbie King - Administrator

Pam Lee - Senior Analyst

Jane Lyon - Clinical Advisor

Kirstin Pereira - Project Manager

Marjan van Waardenberg - Senior Analyst

Email: [firstname\\_lastname@moh.govt.nz](mailto:firstname_lastname@moh.govt.nz) or [cancerteam@moh.govt.nz](mailto:cancerteam@moh.govt.nz)

## **The Bowel Cancer Programme team**

Dr Carol Atmore - Clinical Director

Mhairi Porteous - Programme Manager

Anthony Baker - Senior Project Manager

Susan Hay - Senior Project Manager Quality

Rebecca Hislop - Policy Analyst

Stephen Lungley - Senior Analyst

Ruth McKenzie - Workforce Development Advisor

Virginia Signal - Policy Analyst

Nicola Wilson - Project Manager

Email: [firstname\\_lastname@moh.govt.nz](mailto:firstname_lastname@moh.govt.nz) or [cancerteam@moh.govt.nz](mailto:cancerteam@moh.govt.nz)

Published by the Cancer Team, Sector Capability and Innovation Directorate, Ministry of Health, PO Box 5013, Wellington 6145, Ph +64 4 496 2000. For inquiries about this newsletter please contact: [Emily Barrett](mailto:Emily.Barrett@moh.govt.nz) or phone 027 445 2261