THE NEW ZEALAND MEDICAL JOURNAL Journal of the New Zealand Medical Association



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This Issue in the Journal

The incidence and thickness of cutaneous malignant melanoma in New Zealand 1994–2004

Ann Richardson, Lynn Fletcher, Mary Jane Sneyd, Brian Cox, Anthony I Reeder

Early detection of melanomas picks up melanomas at an earlier stage, and this should eventually lead to a decrease in the incidence of thick melanomas (which tend to have a worse prognosis than thin melanomas). But in New Zealand the incidence of thick melanoma did not decrease during 1994–2004. Of those diagnosed with melanoma, the proportion with thick melanoma was greater for older than younger people, for males compared with females, for Maori compared with non-Maori (despite the lower incidence of melanoma in Maori), and for those diagnosed with nodular melanoma compared with other types of melanoma. Strategies to encourage the early detection of melanoma in New Zealand have not yet reduced the incidence of thick melanomas. This may be because it is too soon to see the impact of early detection, or because early detection strategies predominantly identify melanomas that are unlikely to progress, but miss thicker nodular melanomas.

The road we travel: Māori experience of cancer

Tai Walker, Louise Signal, Marie Russell, Kirsten Smiler, Rawiri Tuhiwai-Ruru, Otaki Community Health Centre, Te Wakahuia Hauora, Te Aitanga a Hauiti Hauora, Turanga Health

This study explored the experiences of Māori affected by cancer in four sites. Whānau (extended family) were included as participants in the study because of the collective nature of Māori society. Participants not only told of the road they travel but made positive suggestions for improvement of the delivery of services to Māori

Thyroid malignancies: a New Zealand South Island thyroid clinic experience 1995–2006

Bevan Brownlie, Philippa Mercer, John Turner, Robert Allison

In the northern half of the South Island thyroid cancer was uncommon (average 18 per year) and the majority of cancers were 'low grade malignancies' (differentiated thyroid cancers). The female-male ratio was greater than 2, and the average patient age was 48 years of age (range 7–86 years). Short-term follow-up (average 6 years) confirms a very good outcome, except in elderly patients with advanced disease. A small number of elderly patients had more highly malignant tumours (poorly differentiated cancers) and few of these survive long.

An audit of colon cancer data on the New Zealand Cancer Registry Ruth Cunningham, Diana Sarfati, Sarah Hill, Diane Kenwright

The New Zealand Cancer Registry collects information from laboratories and hospitals on all cancers diagnosed in New Zealand, and is the main source of information on cancer for planning health services and research. This study assessed the accuracy of the information held on colon cancers diagnosed between 1996 and 2003 by comparing cancer registry records with hospital records. The New Zealand Cancer Registry was found to be similarly accurate to overseas cancer registries, with the stage at which a cancer is diagnosed (whether it is localised or advanced) being the least accurately recorded. Accuracy was over 80% for all the types of information studied, and improved between 1996 and 2003.

The value of voluntary morbidity and mortality meetings at a New Zealand metropolitan hospital

Magdalena Sakowska, Saxon Connor

Audit is undertaken to identify areas of surgical practice and Christchurch Public Hospital where unnecessary complications and death can be minimised. Overall, it was felt that the appropriate treatment pathway had been undertaken in 88% of those patients who suffered a complication and in 91% of those who had died. Despite under-reporting of complications at these meetings, reflecting their voluntary nature, these meetings identify up to 54% of data that is missed or inaccurately recorded by hospital coding. It is unclear what value would have come from discussion of those patients not presented at the meetings. Attendance and the number of patients which have been discussed at these voluntary meetings over the 2-year period has remained stable.

Hospital discharges in New Zealand 1991–2005: changes over time and variation between districts

Antony Raymont

The level of hospital admissions in New Zealand has increased dramatically since 1991 and represents real growth in the intensity of service after allowing for population growth and aging. The rate of real growth has been approximately 1% per annum. Some districts have more, and some have fewer, discharges than would be expected.

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Melanoma in New Zealand: a problem that is not going away

James H F Shaw

In the current issue of the *Journal* Richardson et al¹ present data addressing the incidence and thickness of cutaneous malignant melanoma in New Zealand 1994–2004. Melanoma incidence data prior to 1994 were probably less reliable as for much of the time prior to that date melanoma was not a reportable disease.

In 1999, we published data indicating that the incidence of melanoma in Caucasian (European) patients living in Auckland was 78 per 100,000.² These data were based on analysis of 2 years of reported data after melanoma became a reportable disease. The reason for this difference in our calculation of incidence versus that of Richardson et al¹ are not totally clear.

Interestingly, our findings were confirmed by a study from Waikato³ performed at the same time as our study: they concluded that the invasive melanoma incidence for Caucasians was at least 80 per 100,000 and close to 100 per 100,000 if *in situ* lesions were included.

Possibly the difference in incidence reported jointly in our study² and the Waikato study³ versus the current study¹ may be on the basis that:

- The most recent data are more accurate in view of the fact that they have been collected for the whole of New Zealand and the data collection has been over a 12-year period while our study and the Waikato study were performed over a shorter period of time, or
- Our data were collected all from the greater Auckland area where the melanoma incidence is known to be higher than in most of the rest of New Zealand.⁴

Melanoma is rare in non-Caucasians. In the article by Richardson et al¹ 0.8% of the total melanomas arose in Māori, while 0.16% of the total were observed in Pacific patients; the total incidence for these two groups being less than 1% of the total. It is also well known that the incidence of melanoma in Asian patients is extremely low.⁵

As a consequence, for any given incidence for melanoma in New Zealand overall approximately 99% of patients will be Caucasian. There have been changes to the distribution of ethnic groups in New Zealand over the period 1994 to 2004: According to New Zealand census data the ethnic data are summarised in Table 1.

Table 1. Ethnic demographics and melanoma incidence: overall and in Europeans

Variables	1996	2001	2006
European	76%	74%	68%
Māori	14%	14%	15%
Pacific*	5.4%	6%	7%
Asian / Other	4.6%	6%	10%
Overall melanoma incidence	35 per 100,000	37 per 100,000	37 (estimated) per 100,000
European melanoma incidence	46 per 100,000	50 per 100,000	54 per 100,000

^{*}Mostly of Samoan, Tongan, Niuean, or Cook Islands origin.

As a consequence of the above it would appear that the incidence of melanoma in the racial group making up 99% of the total is actually continuing to increase rather than showing any sign of decrease.

As pointed out by Richardson et al¹ it is unclear whether the failure of incidence to decrease over the 10-year study period is due to the fact that:

- New Zealanders have not taken on the message of avoiding excess sun exposure; or
- That not a long enough period of "sun avoidance" has occurred to allow the melanoma incidence to drop especially taking into account the known long latent period (usually many years) following sun excess prior to the development of melanoma.⁶

What therefore should be done about the high incidence of melanoma in Caucasian New Zealanders? Although a "sun smart" program has been instituted in many parts of the world very few countries have reported any decrease in incidence.^{7,8}.

Persistence in the prevention of melanoma is however clearly the critical management issue. Surgical management of melanoma has become standardized over the past decade: the extent of wide excision of the primary lesion is performed in accord with the thickness of the primary, namely 1 cm clearance for lesions <1 mm thick, while a 2 cm clearance is recommended for thicker lesions.⁹

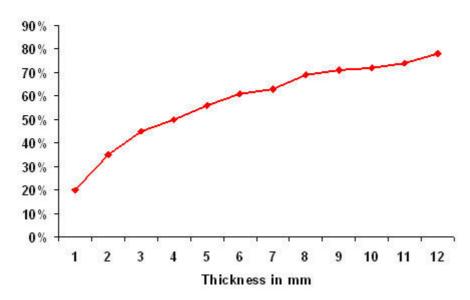
Nodal disease in neck, axilla, or groin is best managed by lymph node dissection occasionally followed by adjuvant radiotherapy, especially following neck dissection. ¹⁰ In addition, the use of sentinel node studies has allowed nodal disease to be detected at an early stage prior to involved lymph glands becoming palpable. ¹¹ Despite this fairly standardised surgical approach the later a patient presents for treatment after the development of a melanoma the worse the outcome as the 10-year mortality for melanoma steadily increases as a function of increased thickness of the primary lesion at presentation. ¹² See Figure 1.

As a result, for patients who have their melanoma detected after it has become >1 mm thick their outlook becomes progressively more bleak. Obviously earlier detection of melanoma while it is still thin (<1 mm thick) is the most effective means of providing better outcomes.

Figure 1

10 yr Mortality 15,320 Melanoma Patients

Modified from Balch et al Jiclin Oncol 19: 3622, 2001



The data of Richardson et al¹ also provide some insight as to which subgroups of the New Zealand population should possibly receive more attention regarding early detection of melanoma.

Table 2 summarises the Richardson data¹ with respect to the patient groups most likely to be at risk of dying from melanoma—i.e. patients with melanomas at presentation >3 mm thick have at least a 50% 10-year mortality.

Table 2. Percentage of patients with melanomas likely to be lethal (>3 mm thickness)—the influence of ethnicity and age

Ethnicity	Caucasian	11%
	Māori	27%
	Polynesian	43%
Age	<60 years	3%
	60–70 years	10%
	70–80 year	15%
	>80 years	29%

Clearly based on these data although melanoma is unusual in Māori and Pacific patients it is these two ethnic groups who present late along with Caucasian patients over 60 years of age. Possibly specifically targeting patients over the age of 60 years may be appropriate, as well as increasing awareness of the fact that although

melanoma is rare in Māori and Pacific patients when it does occur it tends to be missed until it is at an advanced stage.

Overall, although there has been significant progress in the surgical management of melanoma during the period of time addressed in the present study in most parts of the world, including New Zealand, there appears to be no decrease in melanoma incidence despite "sun awareness" programs and in the group of the population most commonly effected, namely Caucasians, the incidence appears to be continuing to increase.

Probably more time and money should probably be spent on awareness campaigns with specific targeting of patient groups over 60 yrs of age who have a high incidence of thick "likely to be lethal" lesions.

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Journal of the New Zealand Medical Association

Ghosts in the machine: the experiences of Māori in the New Zealand health system

Jonathan B Koea

The paper by Walker et al, published in this issue of the *Journal*, describes the journey of Māori undergoing cancer treatment in the New Zealand health system. The paper may not be fully representative of the views of all Māori as it describes the experiences of 44 Māori affected by cancer (both patients and their whānau/families). However the findings were validated at feedback hui and, collectively, the views expressed cover many aspects of the public health system.

A paper dealing with the impressions of a minority population may also be dismissed as having little relevance to most health system users. However the study of health issues in minority populations can also place issues affecting the wider community into sharper focus.

Māori do have a higher cancer burden than non-Māori New Zealanders. Overall the cancer incidence is slightly higher in Māori females than non-Māori females while Māori males have a lower cancer incidence than Non-Māori males.² However site-specific cancer data show that Māori have 3–4 times the incidence of lung cancer, 5 times the incidence of primary liver cancer, and twice the incidence of cervical cancer than non-Māori New Zealanders.

Rates of breast and prostate cancer are similar, while colorectal cancer incidence is half that of non-Māori but rising.² Of more concern are mortality data that show that Māori males and females are nearly twice as likely to die from cancer.³ The reasons for this differential mortality are complex.

Māori are more likely to smoke, to have coexisting diabetes and coronary artery disease, to live in areas of high deprivation, and to be obese. There is some evidence that Māori are more likely to develop aggressive cancer subtypes such as diffuse gastric cancer rather than the intestinal type.² However other factors related to healthcare delivery are also important.

In comparison to non-Māori New Zealanders, Stevens et al⁴ showed that Māori were 2.5 times more likely to present with locally advanced lung cancer, 4 times more likely to receive palliative rather than curative treatment, and had significantly longer transit times from diagnosis to treatment. In addition, Māori were more likely to decline treatment and miss clinical appointments. Consequently Māori represent a demographic with high health need but who generally engage poorly with the mainstream health providers.

So what do Māori want from the health system? Māori providers were praised because of their empathy with patients and whānau and their appreciation of the need for practical assistance such as transport and delivering prescriptions. Overall, patients valued competence, warmth, honesty, respect, and a caring attitude in their health professionals.

Cultural expertise was not mentioned rather a ability to meet patients halfway in terms of cultural needs and the ethnicity of the health professional was less important than the qualities they demonstrated. Poor experiences of Māori in the health system arose when professionals were not perceived as responsive or caring to either patients or their whānau.

The importance of whānau for Māori was also highlighted in the positive comments concerning Ozanam House, a residential facility in Palmerston North for oncology patients and their caregivers. This emphasises that Māori, and many other ethnic groups, function as part of a social collective and service providers and caregivers must recognise this in their service plans. Individually, health professionals must be prepared to communicate with both patients and their whānau and service providers must recognise and resource facilities for whānau to be present and provide support during treatment episodes.

A final common theme was the need for patients to be assertive and actively navigate their way through the health system. This perhaps represents the downside of the complex, multidisciplinary care that we can now provide cancer patients. Multiple therapies involving different providers are utilised at different times and often in different facilities.

Cancer care is undertaken in the context of busy clinics, operating schedules, and inpatient services. Patients who are assertive in their journey through treatment often appear to fare better. However Māori have traditionally valued collective achievement and assertion. For many older Māori, individual advocacy is awkward particularly in the context of clinical encounters with little time for reflection or discussion. Perhaps, as Walker et al¹ suggest, patients now need professional navigators to assist in their movement through treatment algorithms.

The Māori experience of the health system reflects the experience of many New Zealanders. We do many things well. Many health professionals manage and communicate with patients and whānau with expertise, care, and compassion. However our health system has become large and sprawling and we all can become ghosts in the machine attempting to navigate our way through a maze of appointments, admissions, and investigations.

Many Māori health providers were established under the banner of "By Māori, for Māori." The paper of Walker et al¹ highlights the difficulties faced by patients within the mainstream health system and also provides answers from a Māori perspective for many of the issues. This perspective emphasises a patient and whānau-centred approach, practical assistance with day-to -day issues, and adequate time for discussion and education—all universally relevant to patients and caregivers. In the 21st Century the banner for healthcare providers should be "By Māori, for all." **Competing interests:** None known.

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NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716

URL: http://www.nzma.org.nz/journal/121-1279/3200/
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Lack of progress in New Zealand's Cancer Control Strategy

Christopher Wynne

Failure to implement New Zealand's Cancer Control Strategy according to agreed timelines will cost New Zealand many deaths from preventable cancer. The audit of the first 2 years' progress on implementing the strategy (Tracey et al. *Mapping progress: the evaluation and monitoring work of the Cancer Control Council of New Zealand 2005–2007*. http://www.nzma.org.nz/journal/121-1279/3192) gives cause for concern. Eighty-five percent of agreed milestones have not been reached.

The Cancer Control Strategy 2003 is a framework for reducing the incidence and impact of cancer in New Zealand, and reducing cancer-related inequalities. It extends across the cancer continuum from prevention and screening, to treatment, and palliative care. The Cancer Control Council (CCC) is responsible for making sure that the Strategy is turned into action. It is an independent advisory body appointed by the Minister of Health and gives strategic advice to the Minister and the cancer community. Its first key task is to monitor and review implementation of the Cancer Control Strategy. To that end, it agreed on an action plan in 2005, which outlined in detail how the Strategy's objectives can be achieved.

The action plan included measurable goals for 152 milestones to be assessed after the first 2 years of the 5-year action plan. The Council is to be commended for prespecifying the processes of evaluation, monitoring, and reviewing progress in implementation of the plan. If Tracey's article was the basis of a school student's NCEA report card, the report would look like this:

Subjects taken n = 152	
Achieved	15%
Further work required to achieve pass mark	56%
Must start work in these subjects	22%
Has no idea what is happening in these subjects	7%

Although Tracey's paper is described as a viewpoint article, it could also be classified as an audit. Just as clinical medicine can audit treatment outcomes, bureaucracies can audit performance against pre-specified goals. The methods of information acquisition for this audit have revealed ongoing problems. Sector interest groups were asked to provide data to Council specifically for this report, but commented that the data, in many cases, had already been provided to another arm of Government. For any organisation to be efficient, information systems need to be able to provide timely, accurate and relevant data and provider arms should need only to provide input into one system.

The data gathered and reported here by Tracey formed the basis of the Cancer Control Council publication *The first two years of the Cancer Control strategy activation plan* 2005–2010. Following publication of that report, stakeholders—including Ministry of

Health, DHBs, and NGOs—met in late 2007 to discuss progress. Four themes emerged from that meeting:

- The Report was only a point-in-time snapshot but did allow reflection on progress.
- The Report was narrative rather than strategic or analytical. Words such as "achieved" or "in progress" were simplistic, and did not capture the large amount of work that had gone on to achieve milestones in the action plan.
- Issues regarding information acquisition remain a concern.
- Establishment of the regional cancer networks is progressing with varied success. The brief for the networks was not sufficiently described prior to their establishment by the MOH. There is no high level framework that defines the role of the networks and their relationship to DHBs and the CCC.

Feedback has provided clear directions for the Cancer Control Council. Suggestions included: identify key indicators that reflect the breadth of work across the cancer control continuum rather than monitor 152 milestones; actively engage with the Ministry of Health to reduce duplication of monitoring effort; identify project areas where more in-depth investigation would add value to monitoring the action plan; redefine the list of phase II priorities; and ensure sufficient infrastructure is in place for the success of phase II.

It must be noted that the CCC monitors progress, or lack of it, but it is not responsible for implementing the strategy. That is the role of the DHBs and the MOH, hopefully involving NGOs and consumers, presumably co-ordinated by the four regional cancer networks.

The successful cancer control programme in the UK is a model worth revisiting. Unlike New Zealand, significant additional financial resource was applied to the cancer sector including funding of research and treatment. It is possible that New Zealand's slow progress has resulted from failure to commit financial resource despite developing a significant organisational infrastructure. Similarly, the rapid progress in cancer control in NSW, Australia has been achieved by having a clear strategy, strong leadership including an assistant minister of health (cancer services), and improved funding.

In New Zealand, the failure to meet phase I milestones should provide further impetus to the challenge of fighting cancer. There are people with talent; there are organisations with drive and energy, and there are processes in place that should allow successful implementation of the cancer control strategy. The next annual report from the Cancer Control Council should be keenly awaited by all who are interested in reducing the impact of cancer in New Zealand.

Competing interests: None known.

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Defamatory articles or not?

The editorial staff and myself from time-to-time receive abuse from irritated authors about rejection of manuscripts, or about some issue related to publication of their article. However letters from lawyers raise matters to another level. We have previously had the policy to publish all such letters from lawyers and other groups who complain about what we publish. This is done on the basis of openness, a concept that now is a dominate factor in medicolegal circles when dealing with complaints. ¹

Paul Radich, a lawyer who acts for the New Zealand Chiropractors' Association Inc and its members, sent us a letter claiming that two articles in the previous issue of the NZMJ were defamatory.^{2,3}

His letter states:

The article written by Professor David Colquhoun and published by the New Zealand Medical Journal (**NZMJ**) in its 25 July 2008 edition (Vol 121, No 1278) is defamatory of all members of the Chiropractic profession, the New Zealand College of Chiropractic and its President. It is one of the most blatant examples of defamation that we have seen. It is of significant concern that an article in those terms could be written and published in view of the inevitable consequences of those actions.

It asserts, for instance, that 82% of Chiropractors used the title Doctor in order to mislead: that is, they used the title intentionally "to imply that they were registered medical practitioners". It asserts that this is in breach of the law, and that "it seems clear that the law is not being enforced and it is widely flouted". It attacks the chiropractic profession, for instance, by suggesting that it preys on the "weak-minded, ignorant, and superstitious", and that it is "gobbledygook". It states that the idea of giving a qualification in chiropractic is "ludicrous", and such a qualification is "accredited by experts in nonsense". It falsely overstates a risk of death to patients that receive treatment.

The article written by Andrew Gilby [sic] and published by NZMJ is defamatory also. It makes assertions derived from wholly inadequate research, does not detail the criteria upon which its assessments are made thus making statistical "assertions", and considers that use of the title "Doctor" by chiropractors is "not permissible" and that such practitioners are "unlikely" to be complying with the law. The article suggests that this may harm clients seeking healthcare, and attributes various malicious motives to chiropractors' use of the title "Doctor" other than as a legitimate courtesy title.

Each of these statements are defamatory in that:

a the publications tend to lower the entire profession: including the practitioners of that profession; the teachings and concepts of the profession itself; those associated with regulating the profession and its practitioners; and those that are responsible for educating and

- certifying practitioners in the estimation of right thinking members of society generally; and/or
- b the publications contain false statements about the profession, its practitioners, regulators, and educators, that have been published to the discredit of those persons; and/or
- c the publications are published without justification and are calculated to injure the reputation of the profession, its practitioners, regulators, and educators, by exposing them to hatred, contempt or ridicule.

Allegations of such an extreme nature are regarded by the courts as amounting to a clear cut case of defamation.

Before further steps are taken, we request, in accordance with section 25 of the Defamation Act, that Professor David Colquhoun, Mr Andrew Gilby, and Professor Frank Frizelle publish, in the next edition of the publication, with substantially similar prominence, a retraction of the statements in the articles and an apology to the profession, including its practitioners, regulators, and educators. The terms of the retraction and apology must be approved by us before publication.

We request further that the Association on behalf of the profession be given the opportunity to write a reasonable reply to the articles, to be published in the next edition of the publication, and with substantially similar prominence.

In accordance with section 25(2) of the Defamation Act, if this course of action is accepted, you are each, jointly and severally, obliged to offer to pay to the Association, on behalf of the Chiropractic profession:

- a the solicitor and client costs incurred by the Association, its members and its Council in connection with the publication of the retraction; and
- b all other expenses reasonably incurred by the Association, its members and its Council in connection with the defamatory statements that have been published; and
- c compensation for pecuniary loss suffered by the Association, its members and its Council as a direct result of the publication complained of.

We will advise you of the solicitor and client costs and of other expenses incurred upon your agreement to proceed under section 25.

The *Journal*, as with most publications, at times finds itself drawn into a situation in which it must deal with threats of legal action, the history of similar events has previously been published in the NZMJ.⁴

Several issues raised by this letter to the editor are covered in the Uniform Requirements for Manuscript Submitted to Biomedical Journals (http://www.icmje.org/). These requirements continue to evolve and are updated regularly. There is a very good part on publication ethics, which I draw readers' attention to.

The *New Zealand Medical Journal* is one of the group members who helped develop this policy and uniform requirement statements. The uniform requirements state that "The editor of a journal is the person responsible for its entire content".

In the article by Gilbey, data is provided about use of inappropriate titles by New Zealand practitioners of acupuncture, chiropractic, and osteopathy² while the greater context is provided by Colquhoun.³

The comments made by Paul Radich are entirely consistent with the response as expressed by Professor Edzard Ernst (Editor-in-Chief of Focus on Alternative and Complementary Medicine (FACT) and Chair in Complementary Medicine at the University of Exeter) in his humorous article *In praise of the data-free discussion*. *Towards a new paradigm*⁵ when he states "data can be frightfully intimidating and non-egalitarian".

In this issue of the *Journal*, a letter is published from Simon Robb, the Registrar from the Medical Council of New Zealand, which points out similar concerns about the use of inappropriate titles.⁶

Hopefully these articles will fuel more debate about this issue and help define just what really reflects the consumer's expectations of those who use the title doctor.

The *Journal* has a responsibility to deal with all issues and not to steer clear of those issues that are difficult or contentious or carry legal threats. Let the debate continue in the evidence-based tone set by Colquhoun and others.

I encourage, as we have done previously, the chiropractors and others to join in, let's hear your evidence not your legal muscle.

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THE NEW ZEALAND MEDICAL JOURNAL



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Journal of the New Zealand Medical Association

The incidence and thickness of cutaneous malignant melanoma in New Zealand 1994–2004

Ann Richardson, Lynn Fletcher, Mary Jane Sneyd, Brian Cox, Anthony I Reeder

Abstract

Aim To examine the incidence of thick melanoma in New Zealand from 1994–2004 and investigate associations with melanoma thickness.

Method The New Zealand Health Information Service provided information on all registrations for malignant melanoma from 1994–2004. Age-standardised registration rates were calculated. Logistic regression analysis was undertaken to identify factors associated with melanoma thickness.

Results The incidence of thick melanoma did not decrease during 1994–2004. There were statistically significant associations for age, gender, ethnic group, and type of melanoma with melanoma thickness. Of those diagnosed with melanoma, the proportion with thick melanoma was greater for older than younger people, for males compared with females, for Māori compared with non-Māori (despite the lower incidence in Māori), and for those diagnosed with nodular melanoma compared with other types of melanoma.

Conclusion Strategies to encourage the early detection of melanoma in New Zealand have not yet reduced the incidence of thick melanomas. This may be because it is too soon to see the impact of early detection, or because early detection strategies predominantly identify melanomas that are unlikely to progress, but miss thicker nodular melanomas.

Cutaneous malignant melanoma was the fourth most common cancer registration in males and third in females in New Zealand in 2004, the most recent year of published data available from the New Zealand Cancer Registry. Numbers of registrations and age-standardised registration rates are similar for males and females. Non-Māori agestandardised registration rates are about nine times higher than Māori agestandardised rates.1

The forwarding of pathology information indicating cancer to the Cancer Registry became compulsory in New Zealand after the passage of the Cancer Registry Act 1993, which came into effect in July 1994. Increased reporting as a result of this legislation probably explains the observed sudden increase in registrations from 1994 to 1995 in New Zealand.¹

Because the Cancer Registry Act 1993 came into effect in July 1994, increased registration occurred in the second half of 1994, and for all subsequent years. This means that registration data from after 1994 can only be compared cautiously with earlier years.

Since July 1994, melanoma registration in New Zealand is thought to be almost complete (since there are unlikely to be many melanomas which are not histologically diagnosed), so that registration rates can be used as an estimate of incidence.

This paper gives the results of an analysis of melanoma registrations in New Zealand, 1994–2004. During the 1970s and 1980s there had been a marked increase in the incidence of melanoma, followed by a levelling off in incidence in the early 1990s.^{2,3} It had been suggested that this increase in incidence may have resulted from early detection, and that this might be accompanied by a later decrease in the incidence of thick melanomas.⁴

The main purpose of this paper is to provide information on melanoma registrations in New Zealand and, in particular, to see whether there has been any decline in the incidence of thick melanomas.

Method

The New Zealand Health Information Service (NZHIS) provided an electronic data file with all cancer registrations for cutaneous malignant melanoma (C43), including multiple registrations, 1994–2004. The dataset included malignant melanoma only (*in situ* melanoma was not included). Data supplied for 2003 and 2004 were provisional.

Information on melanoma thickness has been recorded by the Cancer Registry since 1994. Breslow's thickness was used as the measure of thickness of the melanomas. This measures in millimetres (mm) the actual thickness of the melanoma, which reflects the depth of penetration into the skin. Tumours less than 1 mm thick (0–0.99 mm) are considered to have the best prognosis, with thicker tumours in general having a worse prognosis. The categories (0–0.75 mm, 0.76–1.49 mm, 1.5–3.0 mm, >3.0 mm) used in this paper are the same as those used in an earlier report on melanoma in New Zealand.⁵

Age-standardised registration rates were calculated using the World Health Organization (WHO) standard population. The NZHIS uses prioritised ethnic group assignment. Prioritised ethnic group assignment means that individuals are designated as Māori if they have included Māori among their options for self-assigned ethnicity, irrespective of how many options they have indicated (including Pacific Island ethnicity).

Individuals are designated as Pacific if they have not included Māori but have indicated Pacific as one of the options. Individuals are designated as non-Māori if they have indicated neither Māori nor Pacific. Prioritised ethnic group assignment was also used in the denominators (derived from census data) for the calculation of the age-specific rates.

Age-standardised rates were also calculated according to thickness. It was important to calculate rates according to thickness (rather than proportions), since an increased detection of melanomas overall (for instance as a result of early detection programmes) could result in a decrease in the proportion of thick melanomas even if the rate of thick melanomas was unchanged.

Logistic regression analysis was carried out to calculate adjusted odds ratios for age, ethnic group, gender, and type of melanoma with respect to thickness at diagnosis (melanoma thickness was categorised as 0-3.0 = "thin" and >3.0 = "thick"). The logistic regression analysis was carried out using the Epi-Info statistical package.

Results

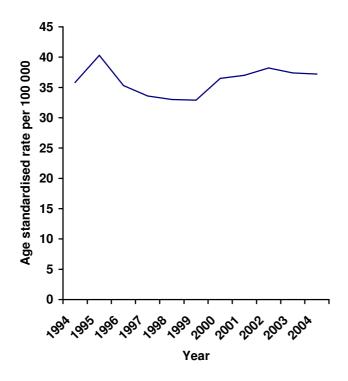
Total registrations for 1994–2004 were 19,435. These included multiple registrations (1,266 registrations for people who had previously already had a melanoma registered). There were 18,169 first registrations for 1994–2004. All tables and figures presented in this paper include first registrations only. Table 1 and Figure 1 show agestandardised registration rates by year, 1994–2004.

Table 1. Age-standardised melanoma incidence rates and 95% confidence intervals (1994–2004)

Year	Number of registrations	Age-standardised rate per 100,000*	95% confidence interval
1994	1458	35.8	33.9–37.6
1995	1672	40.3	38.3-42.2
1996	1510	35.3	33.5–37.1
1997	1482	33.6	31.8–35.3
1998	1506	33.0	31.3–34.7
1999	1503	32.9	31.2–34.5
2000	1696	36.5	34.7–38.3
2001	1753	37.0	35.2–38.8
2002	1835	38.2	36.4–40.0
2003 [†]	1851	37.4	35.6–39.1
2004^{\dagger}	1903	37.2	35.5–38.9

^{*} Standardised to the WHO world population; † Provisional data.

Figure 1. Age standardised melanoma registration rates (1994–2004)



There was an increase in age-standardised registration rates in 1995 compared with 1994, which may reflect increased reporting following the introduction of the *Cancer Registry Act 1993* (which came into effect in July 1994). The rates then declined from 1997–1999. There was little difference in age-standardised registration rates according to gender.

As in earlier reports on melanoma in New Zealand,^{3,5,8} the site of melanoma varied according to gender, with the leg being the most common site for melanoma in

females, while the trunk (torso) was the most common site in males. Table 2 shows registrations by gender and site for 1994-2004.

Table 2. Melanoma registrations by site and gender (1994–2004)

Site	Female	Male
	N (%)	N (%)
Lip	15 (0.2)	21 (0.2)
Eyelid	34 (0.4)	27 (0.3)
Ear	102 (1.1)	280 (3.1)
Face—other	846 (9.4)	881 (9.6)
Scalp and neck	358 (4.0)	744 (8.1)
Trunk (torso)	1675 (18.6)	3783 (41.3)
Arm (including shoulder)	2122 (23.6)	1657 (18.1)
Leg (including hip)	3562 (39.5)	1335 (14.6)
Overlapping areas of skin	6 (0.1)	5 (0.1)
Skin, unspecified	290 (3.2)	426 (3.9)
Total	9010 (100.0)	9159 (100.0)

Results for melanoma thickness in millimetres (Breslow's thickness) are shown in Tables 3 and 4. Thickness data were missing for 2330 melanomas (12.8% overall). Of the missing thickness data, 49% was in the years 1994 and 1995. In subsequent years, less than 10% of melanoma registrations had missing data on thickness.

Melanomas in women were thinner at diagnosis than melanomas in men, χ^2 =62.5, p<0.001 (Table 3). Melanomas in non-Māori non-Pacific people were thinner at diagnosis than for Māori and Pacific people (χ^2 =58.3, p<0.001).

Table 3. Melanoma registrations by Breslow thickness (mm), gender, and ethnic group (1994–2004)

Thickness (mm)	Female	Male	Total
	N (%)	N (%)	N (%)
0-0.75	4289 (54.1)	4000 (50.5)	8289 (52.3)
0.76-1.49	1756 (22.2)	1655 (20.9)	3411 (21.5)
1.5–3.0	1160 (14.6)	1272 (16.1)	2432 (15.4)
>3.0	716 (9.0)	991 (12.5)	1707 (10.8)
Total	7921 (100.0)	7918 (100.0)	15,839 (100.0)
Thickness (mm)	Māori	Pacific*	Other
	N (%)	N (%)	N (%)
0-0.75	36 (33.3)	4 (19.0)	6941 (51.4)
0.76-1.49	25 (23.1)	1 (4.8)	2909 (21.5)
1.5–3.0	18 (16.7)	7 (33.3)	2123 (15.7)
>3.0	29 (26.9)	9 (42.9)	1535 (11.4)
Total	108 (100.0)	21 (100.0)	13,508 (100.0)

^{*}Mostly of Samoan, Tongan, Niuean, or Cook Islands origin.

Table 4 shows that older people had melanomas that were thicker at diagnosis than younger people (χ^2 =1248.4, p<0.0001), with 29% of people aged 80 and older having

melanomas >3.0 mm compared with 5% for people aged 10–29 years. For people over 40 years, the proportion of melanomas >3.0 mm increased with increasing age (χ^2 =591.4, p for trend <0.0001).

Table 4. Melanoma registrations by age group, and Breslow thickness (mm) (1994–2004)

Age group (years)	0-0.75 mm N (%)	0.76–1.49 mm N (%)	1.5–3.0 mm N (%)	>3.0 mm N (%)
0–9	2 (66.7)	1 (33.3)	0 (0.0)	0 (0.0)
10-19	64 (54.2)	24 (20.3)	24 (20.3)	6 (5.1)
20-29	448 (64.0)	137 (19.6)	80 (11.4)	35 (5.0)
30–39	976 (62.8)	375 (24.1)	156 (10.0)	48 (3.1)
40–49	1583 (60.5)	602 (23.0)	288 (11.0)	142 (5.4)
50-59	1696 (56.3)	707 (23.5)	414 (13.7)	194 (6.4)
60–69	1536 (50.4)	675 (22.1)	528 (17.3)	310 (10.2)
70–79	1383 (45.8)	599 (19.8)	578 (19.1)	460 (15.2)
80+	601 (34.0)	291 (16.5)	364 (20.6)	512 (29.0)
Total	8289	3411	2432	1707

Figure 2 shows age-standardised rates according to Breslow's thickness. There was no decline in the age-standardised incidence of thick melanomas (greater than 3.0 mm) from 1994–2004.

Figure 2. Age standardised melanoma rates according to Breslow's thickness (mm) 1994–2004

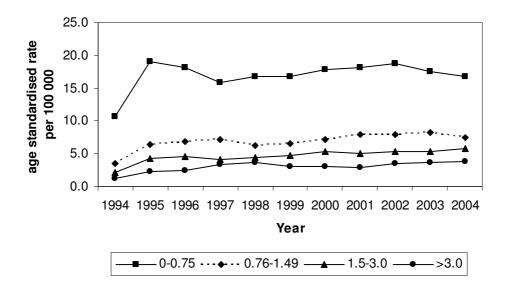
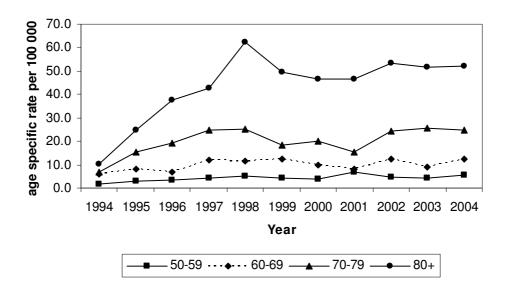


Figure 3 shows annual age-specific incidence rates for thick melanoma (>3 mm), 1994–2004. The rates for younger people were unstable because of small numbers of

thick melanomas registered in each year in young people, so data for people aged less than 50 years at diagnosis are not shown. It appears that the incidence of thick melanoma during the time period studied increased more steeply for older people (80 years and over) than for younger people.

Figure 3. Age-specific incidence of thick melanoma (>3 mm) (1994–2004)



Among those diagnosed with melanoma, significant associations were found between age, gender, ethnic group, type of melanoma, and the thickness of melanoma at diagnosis (Table 5). Of those diagnosed with melanoma, the proportion with thick melanoma (>3.0 mm) was greater for older than younger people, for males compared with females, for Māori compared with non-Māori (despite the lower incidence in Māori), and for those diagnosed with nodular melanoma compared with other types of melanoma.

Table 5. Melanoma thickness and age, ethnic group, gender, and type

Variables	Odds ratio*	95% confidence interval
Age		
(10-year age groups)	1.54	1.48–1.60
Ethnic group		
(Māori / non-Māori)	4.34	2.56–7.15
Gender		
(Female / Male)	0.80	0.71-0.90
Melanoma type		
(Nodular / other)	11.23	10.00–12.69

^{*} Odds ratios adjusted for all other variables in the table.

Discussion

Over 18,000 New Zealanders were diagnosed with a primary melanoma during 1994–2004. Following an increase in registrations in 1995 (which may be partly the result of increased reporting following the passage of the *Cancer Registry Act 1993*), agestandardised incidence rates declined during 1997–1999 and then increased.

Male and female age-standardised incidence rates were similar, but the site of melanoma differed by gender, with the leg being the most common site for females, while the trunk was the most common site for males. Age-standardised incidence rates according to thickness showed no decrease in the incidence of thick melanoma in New Zealand during 1994–2004. At the time the data were provided, registrations for 2003 and 2004 were provisional. The numbers of registrations for 2003 and 2004 may alter slightly but this is not expected to change the conclusions reached here.

Little has been published about trends in the incidence of melanoma by thickness in New Zealand, and comparisons with overseas studies are complicated by the use of differing definitions of "thick" melanoma. During a similar time-period (1993–2003) to our study, there was no decrease in the incidence of thick melanoma (defined as >4.0 mm) among females or males in Yorkshire.⁹

The incidence of thin melanoma increased in Southern Germany during 1976–2003 while the incidence of thick melanoma (defined as >2 mm) remained stable. ¹⁰ In Scotland, during 1979–2003, the percentage of melanomas defined as thick (>4.0 mm) fell but the actual incidence remained stable for those aged less than 60 years and increased for those aged 60 years and over. ¹¹

There was no decrease in thick melanomas (defined as 1.0 mm or greater) in Queensland, Australia, although incidence rates increased more slowly for thick melanomas than for thin or *in situ* melanomas.¹² A decline in the incidence of thick melanoma (defined as >3.0 mm) has been reported from Victoria, Australia, but the only published source for this is a conference abstract.¹³

One study of trends in melanoma in Germany, Austria, and Switzerland during 1976–2000 reported decreases in the median thickness of melanomas and the proportion of melanomas >4.00 mm, ¹⁴ but these results are difficult to interpret, since decreases in the median thickness or the proportion of melanomas which are thick can be found despite an unchanged incidence of thick melanomas (as demonstrated in Scotland by MacKie et al). ¹¹

Increasing early detection of melanoma had been thought to partly explain the increasing incidence of melanoma in countries such as Australia, New Zealand, and the US during the 1970s and 1980s. Ideally, increasing awareness should lead to increasing incidence of thin lesions, and after a delay, a corresponding decrease in the incidence of thicker lesions. Despite this expectation, such a decrease in thicker lesions had not been reported in Australia in the 1990s, which led to the hypothesis that some of the thin lesions are "non-metastasising" melanomas.¹⁵

Strategies to encourage the early detection of melanoma in New Zealand do not seem to have produced a decline in the incidence of thick melanomas so far. It may be that it is too soon to see the impact of early detection or prevention strategies yet. It has

been suggested that the impact of early detection strategies is unlikely to be seen earlier than 20 years following the implementation of such strategies. 12,16

The absence of a decline in the incidence of thick melanomas could also be consistent with early detection strategies failing to identify those melanomas most likely to progress, as suggested by Burton and Armstrong.¹⁵ If this is so, more attention may need to be given to the early detection of melanomas which are most likely to progress, such as nodular melanomas, which comprise a high proportion of thick melanomas in New Zealand and in the US and Australia.^{17,18}

Competing interests: None known.

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Acknowledgments: The New Zealand Health Information Service provided the melanoma registration data from the New Zealand Cancer Registry, and the Cancer Society of New Zealand funded the extraction of the data. The University of Otago Director's Cancer Research Trust provided support to BC and MJS. The Cancer Society of New Zealand Inc and the University of Otago provided support to AIR and the Social & Behavioural Research Unit.

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The road we travel: Māori experience of cancer

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Abstract

Aim This research explores Māori experiences of cancer. It does so to shed light on the causes of cancer inequalities for Māori.

Methods The views of 44 Māori affected by cancer—including patients, survivors, and their whānau (extended families)—were gathered in five hui (focus groups) and eight interviews in the Horowhenua, Manawatu, and Tairawhiti districts of New Zealand. After initial analysis, a feedback hui was held to validate the findings.

Results Māori identified effective providers of cancer services such as Māori health providers. They also identified positive and negative experiences with health professionals. The involvement of whānau in the cancer journey was viewed as highly significant as was a holistic approach to care. Participants had many suggestions for improvements to cancer services such as better resourcing of Māori providers, cultural competence training for all health workers, the use of systems 'navigators', and the inclusion of whānau in the cancer control continuum.

Conclusion The research identifies a range of health system, healthcare process, and patient level factors that contribute to inequalities in cancer for Māori. It also explores the role of racism as a root cause of these inequalities and calls for urgent action.

Cancer is a leading cause of death for Māori. It contributes significantly to the difference in life expectancy at birth between Māori and non-Māori. From 1981–2004 Māori cancer mortality rates increased for all cancers combined; whereas non-Māori non-Pacific cancer mortality decreased. Māori are 18% more likely than non-Māori to be diagnosed with cancer and have a 93% higher mortality rate. ²

Cancer control has received increased focus in New Zealand since the development of *The New Zealand Cancer Control Strategy*.³ The *Strategy*'s overall purpose is to reduce the incidence and impact of cancer and reduce inequalities with respect to cancer. The first principle of the *Strategy* is to 'work within the framework of the Treaty of Waitangi to address issues for Māori'.

To address the startling inequalities in cancer for Māori, it is critical that Māori experience of cancer is understood and acted on. However, there is a little written from a Māori view about Māori experience of the cancer journey. There is also limited literature that illuminates the causes of Māori cancer inequalities—but what there is focuses on three key areas (health system, healthcare process, and patient factors) as outlined by Cormack et al. ⁴ In taking this approach, Cormack et al. build on the work of Mandelblatt et al.. ⁵ Cormack et al. note that access to cancer care is 'complex and multidimensional'. Health system level factors 'include the focus of the

cancer care system and services, funding and resources, service configuration and location, workforce, availability of information and resources, and expense'.⁴

In the New Zealand context, a nationally representative sample of general practitioners found financial and cultural factors, amongst others, as key barriers to health care for Māori.⁶

Healthcare process factors include 'the way that services operate and work with other services, characteristics of physicians/providers such as training, competence, perceptions and biases, and patient-provider interaction'.⁴

Crengle et al., reporting on the same national study of general practitioners discussed above, noted that general practitioners had lower levels of rapport with Māori than with non-Māori patients. In addition, Māori visited the doctor fewer times per year and their consultations were shorter than those of non-Māori. Reasons why providers give less and lower quality care to Māori may include lack of a shared cultural or social background and lack of understanding.

Rapport is a key facilitator of access to healthcare, but notions of rapport are culturally bound. Components of rapport include 'the doctor taking time to listen, using understandable language, taking an interest in whānau health history, and engaging with the patient to deliver a collaborative style of healthcare'. Pākehā (New Zealand European) doctors may believe they have established rapport with Māori patients, when in fact they have not.

At a patient level, key factors are 'socioeconomic position (including deprivation, employment conditions, and insurance status), transportation, and patient context'.⁴

Māori carry a much higher burden of deprivation than non-Māori. Deprivation combined with racial discrimination accounts for much of the disparity in health between Māori and non-Māori. Māori take a holistic approach to health which is inconsistent with a traditional medical approach. Cram et al. note that Māori carry knowledge of previous negative experiences between Māori, and Pākehā health professionals.

While this literature is disparate, nevertheless, a number of studies highlight serious and complex issues in relation to health inequalities for Māori that require urgent attention. They include health system, healthcare process, and patient factors. To tackle inequalities, we must understand their root causes.

Harris et al. discuss the effects of a key root cause—racism—based on data from the 2002/2003 National Health Survey. ^{9,11} Data showed 'that self-reported experience of racial discrimination was highest among Māori and that any such experience was strongly associated with negative health effects equally for all ethnic groups'. ⁹

This current research aims to explore Māori experiences of cancer in their own words. It does so to shed some light on the causes of cancer inequalities for Māori.

Methods

This research is a qualitative study of the experiences of Māori affected by cancer including patients, survivors, and their whānau. Qualitative methods were chosen because they allow for in-depth exploration of a topic. ¹² Including whānau members reflects the collective nature of Māori society. The fieldwork was conducted between late 2004 and mid 2005. Two data collection methods were used:

- Five hui/focus groups: 44 participants in four sites in Horowhenua, Manawatu, and Tairawhiti.
- Eight kanohi ki te kanohi (face-to-face) interviews with cancer patients and survivors in the same regions.

Participants were recruited by the Māori health providers who were partners in this research and knowledgeable about Māori affected by cancer in their area. All participants were of Māori descent; from their early 20s to mid-70s. While most participants had current experiences of cancer (e.g. in the last 5 years), some had experiences dating back 20 to 30 years.

An interview schedule was developed by the research team for the hui and interviews. The questions were designed to explore with participants their experience and information needs at diagnosis, treatment, prognosis, the availability of services, and their knowledge of the Cancer Society. Participants also focussed on other issues of relevance to them in relation to their cancer journey.

The analysis was done in two stages. A thematic data analysis undertaken by the Wellington-based researchers identified key themes. In addition, the team focussed on identifying specific Māori messages within the data. Then a feedback hui was held at the Cancer Society's Manawatu Centre with research participants, Māori health providers, and Cancer Society staff.

The Wellington researchers presented the results and sought feedback from those present. Hui participants' responses were then used to validate the findings and further analyse the data. Ethical approval for the study was obtained from the Tairawhiti, Manawatu, and Wellington Ethics Committees.

The research was conducted in the Cancer Society central region. Māori, as a rule, are relativistic and do not claim to speak for all Māori including those living in other regions. Therefore this paper does not claim to be generalisable to other Māori in New Zealand. However, this does not mean that the experiences and lessons learnt from this study do not apply to Māori in other regions.

Results

Māori providers

There was high praise for Māori providers, for their grounding in a Māori/iwi (tribal) worldview, their style of practice, and their support for Māori affected by cancer. Māori providers gave important practical assistance—e.g. transport to the doctor or hospital, collecting and delivering prescriptions, and even having an ambulance alarm connected. They were available to both the cancer patients and their whānau.

'Māori health providers will go that step further' said a participant. Māori providers practised an awhi (supportive) approach, and whakawhānaungatanga (building on relationships). Recognition by Māori providers of their taha Māori (Māori being) was important to participants because it is 'who and what they are', and providers' strong, 'awesome' links with iwi were valued.

The wife of a patient with throat cancer praised a Māori doctor who asked her what she wanted to know. She asked to view her husband's throat, and the doctor organised this with the specialist, giving her reassurance.

Ozanam House

Ozanam House is a residential facility in Palmerston North for cancer patients and whānau from the Central Districts region who are using the Regional Cancer Treatment Service. Participants with experience of Ozanam House had nothing but praise for it as a supportive institution that met their needs very well. Strengths of this 'whānau house' identified by participants included: 'that whānau can stay there', 'there are mattresses in the lounge' [like on a marae], 'you cook your own food', and 'you can talk with others about your experiences'.

Experiences with health professionals

Participants had both positive and negative experiences with their doctors, nurses, and hospice staff. In particular, they valued good communication. One participant felt fully informed about treatment and the duration and effects of medication. Another noted that, during a lengthy surgery, doctors maintained good communication with whānau members.

A further participant noted that good communication between her oncologist and general practitioner, 'made it a lot easier for me and it played a big part in my recovery'. Another participant's doctor, 'told me exactly what was wrong, where it was, and what they were going to do and I thought it was wonderful...all the way through there was this supportiveness'. Some participants' doctors and specialists had given out their phone numbers for day and night contact.

While participants praised good services, they also noted where professionals were not responsive to their needs. One said 'some medical professionals are like WINZ (New Zealand's social security agency), unless you ask the questions you don't get the answers ... and the trouble is if you don't know the question you don't get the answer. How can you ask?'

Another noted that doctors were 'fee driven'. Another participant felt 'there's a judgmental thing with some [doctors] but not all of them'. A further participant reported that a doctor had a 'bad attitude'. A grandmother described the treatment her mokopuna (grandchildren) received as 'unbelievable, like a horror story' and commented that the doctor in question had 'no aroha' (love/compassion).

Another participant had 'to bully the doctor to get a commode and pain relief' for her sister and she had 'to work hard to get them', although 'we didn't want much'. A survivor of cervical cancer was unaware of the impact of having both ovaries removed and would have opted to keep one if she had known it would put her into early menopause.

In each area there was at least one case of misdiagnosis reported. In one case, the correct diagnosis was made when the survivor sought a second opinion. Three survivors described feelings of anger that the misdiagnosis had occurred and were traumatised by the experience.

Participants who worked in the health sector noted that it would be difficult for Māori who were not assertive or proactive to receive the level of care they required. One of these health workers had been unaware of the fact that she could have had a reconstruction at the same time she had a mastectomy operation. She was also unaware of the negative impact of treatment on her sexuality. In one case, a survivor had surmised that his cancer was under control, stating that 'it must be OK' because he had not had a note from the specialist to return for a check.

Nurses were important providers of services, information, and support. One participant spoke of the value of nurses who were caring, understanding, and positive because they provided the reassurance that patients needed. An oncology nurse who visited a participant at home provided a copy of all her notes on request.

By contrast, the information from the hospital on her chemotherapy was one illegible photocopied page. A Māori nurse on her days off helped another participant care for

his dying mother. This was the only support that was offered. Another participant noted that the hospice staff provided a lot of information during home visits.

In health professionals, participants valued competence, compassion, warmth, honesty, respect, and professionals who offered support and took an interest in them, meeting them halfway in terms of cultural needs. One participant said that having a Māori health professional 'made it easier for me' because she was able to 'relate' and felt that the health professional 'related' well to her.

'I just expect a little bit of civility and courtesy and I'm happy'. Participants preferred finding out about their cancer from a person they could trust and feel at ease with, preferably someone with whom they had an established relationship. As one person explained; the 'personal touch made a big difference'. The participants indicated that, for the majority of patients and whānau, the ethnicity of health professionals was less important than the qualities they demonstrated.

The importance of whānau

Whānau involvement in the cancer journey as well as the support whānau gave were seen as highly significant. Whānau fulfilled many roles such as providing support and 'strength' for the person in hospital, nursing care in the home, acting as advocates with health professionals, information-gathering and responsibility for medication. A participant said, 'you won't survive if you don't have the support of your whānau'.

Whānau need knowledge of the entire cancer journey as a participant explained:

...whānau need to know about the illness, what course it can take, what symptoms can appear, about different medications, why they are taking it, how it can help them, and about the side effects. They need to know that there is somebody they can contact if they should have any difficulties.

The responsibility to care for whānau and the cost of this to whānau was also highlighted. One participant cautioned that whānau need to be aware of the extent of their responsibilities when they said 'you [whānau] have to be prepared to go the whole nine yards, totally there for their benefit'. Another participant, while delighted that her children wanted to care for her, was also concerned that they continue their paid employment.

Holistic aspects of health

As well as the medical treatment they received, most participants also sought emotional and spiritual support from within their own culture. Holistic approaches included mirimiri (massage), the application of kawakawa leaves, metallic healing, reiki, and reflexology. 'The hospital deals with your physical problems but they do not deal with your mental and spiritual problems'.

At the feedback hui (meeting), Māori spoke of the need for a mixture of the clinical and the holistic aspects of health that takes into account wairua (spirituality), whakawhānaungatanga (relationships, and whakapapa (genealogy), 'so we [Māori] are all comfortable and we all feel that we are being treated how we feel we should be treated'. Doctors should be trained in these 'important aspects for Māori'.

Making your path a bit easier

Suggested improvements included health system, healthcare process, and patient factors.

- Staff to alert Māori to their entitlements—e.g. transport, benefits, home help, equipment.
- Co-ordinated service delivery, to avoid 'getting the run-around' from service to service.
- More frequent specialist clinics for rural participants.
- Flexibility in accommodation arrangements—e.g. 'an extension of the rapuora concept, namely where people can stay for a number of days' to get the care rural participants need [given that they often travel for treatment].
- Staff to be 'aware of what it is to be Māori and where Māori come from...and what we have had to give up. We have our own uniqueness and we are a diverse people'.
- Staff to accommodate tikanga (cultural practices), wairua (spirituality), hinengaro (emotional and mental), tinana (physical), and whānau (Māori family forms).
- Providing a person to help navigate across the cancer control continuum, 'someone to make your path a bit easier'.
- A care plan at diagnosis would enable whānau to work through and manage the cancer process.
- Māori support groups for cancer patients, survivors and their whānau.
- Counselling and support for whānau.
- Systems in place that provide good information to everyone preferably kanohi te kanohi or face-to-face, with written material providing support.
- An increased Māori workforce including Māori oncology nurses and a liaison person.
- Preventative education.
- Choice for female patients to have women health professionals.
- An explanation of the impact of treatment on patients, e.g. on their sexuality.

Discussion

The present study examined the experience of Māori cancer patients, survivors and their whānau by providing them with opportunities to discuss their cancer journey in their own words. Participants' discussion can be framed by Cormack et al. and Mandelblatt et al.'s analysis of inequalities in access to cancer services as follows.^{4,5}

In terms of health system factors, participants in this research identified Māori health providers and Ozanam House as examples of services that work for Māori. Māori also identified a number of ways to improve services including co-ordinated service

delivery, informing Māori of their entitlements, an increased Māori workforce, systems in place that provide good information (preferably face-to-face), support and counselling for patients and whānau and more regular provision of services in rural areas.

Māori providers with a Māori worldview, provide practical support to Māori experiencing cancer and are a conduit between the patient and the cancer control system. This research suggests that the work of Māori providers should be extended and further resourced because of its importance in ensuring quality cancer control services for Māori. However, 'since the majority of Māori continue to receive most of their health care from mainstream services, considerable ongoing effort is required to reorient mainstream services, providers, and systems to prioritise Māori health needs'. ¹³

Ozanam House provides some clues about how to proceed. It is a mainstream organisation that successfully accommodates the needs of Māori, providing a place where Māori experiencing cancer can be Māori.

At the healthcare process level participants across the four sites reported varying quality. People working in the health system were reported as unable at times to establish rapport, a key issue discussed by Cram et al.⁸ This research demonstrates the need for significantly improved cultural competence training and ongoing assessment of cultural competence of all health professionals, including important gatekeepers such as receptionists and administration staff.

It also shows that an increased Māori health workforce is urgently needed. Indeed, people to assist Māori in navigating the health system will be a valuable addition. Anecdotal evidence from Canterbury District Health Board suggests that the employment of a Māori navigator in the cancer control arena results in improved service delivery for Māori (personal communication, Kaitiaki Oncology, 2006).

At the patient level, the research underscores the importance of whānau involvement in the cancer journey and taking a holistic approach to health. This supports findings by Cram et al. The research suggests that the concept of the 'cancer control continuum' should include patients and whānau who support and care for the patient. This view implies different priorities, and different ways of working from the concept that sees the continuum in terms of the cancer control workforce.

The health system benefits from the care and support that whānau provide. Whānau need support and adequate resourcing in this role. But their involvement should not replace appropriate support from cancer control services that have an obligation to deliver services fairly to all. This support may need to come from outside the health sector and may require intersectoral action on the part of the health sector in areas such as education, employment and income.

There is an expectation that the New Zealand health service is a level playing field. However, discrepancies in access to quality health services by Māori are beginning to be documented. Too often, participants in this study expressed considerable gratitude for very limited care. This research indicates an urgent need to ensure that Māori receive the same 'gold standard' service to which all New Zealanders are entitled.

This research provides some valuable pointers as to how to achieve this—such as:

- Coordinated service delivery,
- Meaningfully informing Māori of their entitlements,
- Better resourcing of Māori providers,
- Altering mainstream services to support Māori,
- Increasing the Māori workforce,
- Cultural competence training for all health workers,
- The use of systems 'navigators', and
- The inclusion of whānau in the cancer control continuum and adequately resourcing them.

Recent work on racism as a root cause of inequalities in health provides a further level of analysis for this research. Reid and Robson state that 'racism is a major determinant of health and a fundamental driver of inequalities that must be addressed in order to improve Māori health outcomes and reduce inequalities'. 16

Jones has developed a framework for understanding racism on three levels—institutionalised, personally mediated, and internalised—and has applied it to health. ¹⁷ She argues that 'this framework is useful for raising new hypotheses about the basis of race-associated differences in health outcomes, as well as for designing effective interventions to eliminate those differences'. ¹⁷

Applying this framework to the current research *institutionalised racism* is where Māori are being structurally excluded from equitable access to health services on the basis of ethnicity; *personally mediated racism* is where health workers make differential assumptions about Māori and treat Māori inadequately; and *internalised racism* is where Māori appear to expect differential lesser treatment (often based on past experiences) personally or within their whānau.

Research on the experiences of Māori across the cancer control continuum and at health systems, healthcare processes, and patient levels is limited as is an analysis of the role of racism in driving health inequalities.

Further research and action is urgently needed as a result if the gap between Māori and non-Māori in relation to cancer is to close. The present research provides valuable information on Māori experience of cancer from a Māori view.

It is critical that these findings are urgently enacted through the Government's *New Zealand Cancer Control Strategy* if the *Strategy* is to deliver on its purpose and address its principles.

Competing interests: None known.

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NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716

URL: http://www.nzma.org.nz/journal/121-1279/3193/

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Acknowledgements: Ngā mihi nui kia rātau mā i homai ō rātau whakaaro rangatira, me ō rātau mamaetanga hoki. Kia rātau kua ngaro kit te po haere, haere.

The research team would like to thank the participants who shared not only their experiences and insights but also their pain. For those who have passed on, haere, haere, haere (farewell, farewell, farewell). A special thanks to John Waldon and Virginia Signal for their unstinting support. Our thanks also go to Dr Kevin Dew and Donna Cormack (from the University of Otago) as well as two anonymous reviewers for their valuable comments on an earlier draft of this paper. This project was funded by a Grant-in-Aid from the National Scientific Committee of the Cancer Society of New Zealand (Inc). We also thank the Cancer Society Central Districts Division Inc—Manawatu Centre and the Gisborne East Coast Cancer Society.

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Thyroid malignancies: a New Zealand South Island thyroid clinic experience 1995–2006

Bevan Brownlie, Philippa Mercer, John Turner, Robert Allison

Abstract

Aim To assess the number and histological type of thyroid malignancies occurring in the northern half of New Zealand's South Island (referral population of 553,000).

Methods Patients with newly diagnosed thyroid malignancies seen at thyroid clinic, Christchurch Hospital between 1995 and 2006 were identified from the thyroid clinic database, and the histological diagnoses and clinical features were reviewed from hospital records.

Results During the 12-year study period, 213 patients with thyroid malignancy were identified. The majority had thyroid cancer of follicular cell origin—184 differentiated thyroid cancers (DTC) and 9 anaplastic thyroid cancers. The DTC patients included 130 with papillary thyroid cancers (PTC)—71%; 33 follicular thyroid cancers (FTC)—18%; and 21 Hürthle cell thyroid cancers (HTC)—11%. One of the papillary cancer patients had a mixed papillary-medullary tumour. The 184 DTC patients included five patients with an immediate family member with thyroid cancer—including a mother-son pair with papillary cancer. Tumours of nonfollicular cell origin included 12 medullary thyroid cancers (6% of primary thyroid malignancies), and all were apparently sporadic, 7 primary thyroid lymphomas, and 2 thyroid metastases. The female-male ratio was ≥2 in all patient groups with primary thyroid malignancies. The median age for both PTC and FTC groups was 48 y, with Hürthle cell, anaplastic, and lymphomas occurring in older patients. The 3 paediatric patients (<16 y) all had PTC.

Conclusions In the 12-year study period the majority (90%) of thyroid malignancies were of follicular cell origin—184 DTC (papillary 130, follicular 33, and Hürthle 21), and 9 anaplastic cancers. Tumours of non-follicular cell origin were uncommon and included medullary cancers, lymphomas, and metastases. Short-term follow up (median 6 y) confirms that anaplastic thyroid cancer is highly malignant, and the only patients with differentiated thyroid cancer with early cancer deaths had presented with advanced disease and were > 55 years at diagnosis.

Thyroid cancer is responsible for 1% of New Zealand cancer registrations. In New Zealand, and in other developed countries the incidence of thyroid cancer is increasing and it is uncertain whether this is because of changed histological criteria, better diagnostic procedures or environmental factors.

The New Zealand thyroid cancer incidence rate has risen between 1971 and 1996 from 3.7 to 6 per 100,000 females and 1.7 to 2.6 per 100,000 males; and the mortality rate has shown a steady downward trend. Thyroid cancer is one of the few cancers with female incidence greater than in males.

The majority of thyroid malignancies are of follicular cell origin, and differentiated thyroid cancer (DTC) is an indolent tumour with a very good prognosis following adequate surgery and postoperative radioiodine therapy.³ Adverse indicators include age greater than 45 y, primary tumour greater than 4 cm in diameter, extrathyroidal invasion, and distant metastases.⁴ In contrast, anaplastic thyroid cancer is highly malignant.⁵

A small proportion of thyroid malignancies are of nonfollicular cell origin and include medullary thyroid cancers of C cell origin, and primary thyroid lymphomas.^{6,7}

The Thyroid Clinic at Christchurch Hospital established a database of diagnoses from the beginning of 1995. In this report we document the number of newly diagnosed thyroid malignancies identified on the database from patients referred to our service over the last 12 years. Clinical data and histological classification are presented, and preliminary outcome data is also reported.

Patients

The patients recorded on the database had been seen at Christchurch Hospital thyroid clinic, which is a referral centre for the northern half of the South Island with a population of 553,000—included patients were from Canterbury, South Canterbury, West Coast, and Nelson areas. The population is largely Caucasian, and in the Canterbury area currently some 8% are Māori and 6% Asian.

The management of thyroid malignancies in Christchurch is by a multidisciplinary team including thyroid physicians, endocrine surgeons, ENT surgeons, and oncologists. Patients included those initially diagnosed at thyroid clinic, plus patients referred for further management from surgeons in the public and private sectors. A small proportion of patients were seen in the Oncology Department where they had been referred for management of anaplastic thyroid cancer or lymphoma.

Initial investigations for the majority of patients included nuclear medicine scans or thyroid ultrasound, and fine needle aspiration cytology. Histological diagnosis was confirmed following tumour resection, or in inoperable cases by open biopsy. World Health Organization (WHO) pathological criteria were used to classify the primary tumours with peer review, and when necessary further review by international histology consultants. The original pathology reports were used, and not revised using the latest (2004) WHO criteria.

This study was confined to newly diagnosed thyroid malignancies, and patients diagnosed and treated elsewhere in New Zealand or overseas were excluded from analysis, and one patient treated in Christchurch but referred from Southland was also excluded.

Results

In the 12-year study period, 213 patients with newly diagnosed thyroid malignancy were identified from the thyroid database. The distribution of the histological types of thyroid malignancy is shown in Figure 1. The greatest proportion (193) were tumours of follicular cell origin—184 differentiated thyroid cancers (DTC) and 9 anaplastic cancers. The differentiated tumours included papillary thyroid cancers (PTC),

follicular thyroid cancers (FTC), and Hürthle cell thyroid cancers (HTC)—alternatively classified as oncocytic thyroid cancers. 9

Malignancies of nonfollicular cell origin included 12 medullary thyroid cancers of C cell origin (almost 6% of malignancies), 7 primary thyroid lymphomas (3%), and 2 thyroid metastases. One tumour was a mixed papillary-medullary cancer (papillary measuring 21 mm merging with the smaller medullary cancer measuring 9 mm) and features as a 'double entry' with papillary cancer on our thyroid data base (213 patients with 214 malignancies).

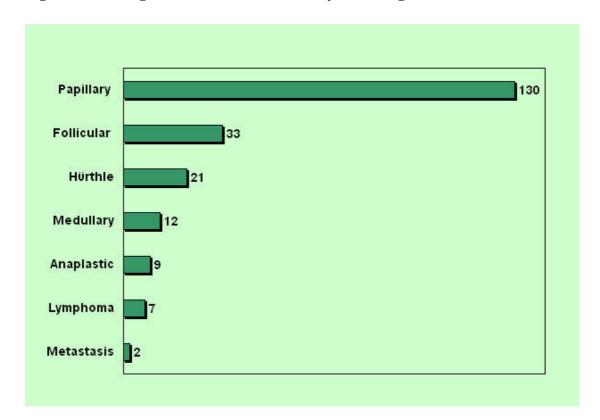


Figure 1. Histological classification of 214 thyroid malignancies: 1995-2006

Papillary thyroid cancer was by far the commonest thyroid malignancy, with the 130 patients making up some 71% of DTC with only 2 PTC primary tumours having significant areas of poorly differentiated cancer, and 2 tumours were tall cell variants. Twenty-two of the papillary cancers were diagnosed following surgery for benign thyroid disease—17 of these 'incidental thyroid cancers' were micropapillary cancers (mPC) measuring less than 1 cm in diameter.

Follicular cancer made up the second largest group—33 tumours—18% of DTC, and almost half (15/33) were minimally invasive tumours, with 2 FTC tumours showing significant poorly differentiated areas. Hürthle cell cancer made up the third largest group—21 tumours (11% of DTC).

Most thyroid malignancies presented as a thyroid mass, and 2 midline masses were cancers in thyroglossal remnants—from middle-aged patients, 1 with a cystic PTC, and 1 with a solid FTC. More than 10% of PTC patients initially presented with cervical lymphadenopathy, and other atypical presentations included 2 patients with upper airways obstruction caused by intratracheal tumours (both PTC), and 3 patients presented with bone metastases (large sternal mass—2° PTC, back pain—2° FTC, and back and hip pain—2° HTC).

The age and sex distribution of the patient groups is summarised in Table 1. The female-male ratio was ≥2 in all patient groups with primary thyroid malignancies. The median age for both papillary and follicular cancer patients was 48 y, with Hürthle cell, anaplastic and lymphomas occurring in older patients. Only 3 paediatric (<16 y) patients were diagnosed; all 3 had papillary tumours and the youngest patient aged 7 years presented with cervical lymphadenopathy and lung metastases. Although there were no paediatric patients with follicular cancer it is of interest that the two youngest patients with FTC (females aged 16.5 and 22 y) both had a history of prior abdominal malignancies in childhood—germ cell malignancy and Wilm's tumour respectively.

The patients with differentiated thyroid cancer (total 184) included 5 patients with a sibling or parent with previously treated thyroid cancer—4 patients with papillary cancer (including a mother and son) and 1 patient with follicular cancer. No patients belonged to a family with familial adenomatous polyposis (FAP) which is known to be associated with papillary thyroid cancer, but the youngest patient with follicular cancer has since been identified as having Cowden's disease (multiple hamartoma syndrome). None of the 12 patients with medullary thyroid cancer had a family history of thyroid malignancy, and genetic screening of patients for RET oncogene mutations since 1999 has been negative.

No patient in the series gave a history of neck irradiation in childhood, but 4 patients with DTC gave a history of neck radiation in adulthood—3 had previously received radioiodine treatment, 2 for toxic nodules, 1 for nontoxic multinodular goiter, and 1 patient gave a history of prior external beam radiation treatment for ipsilateral breast cancer.

Preliminary outcome data with median follow up of 6 years is included in Table 1. The largest group of patients with papillary and follicular cancers (combined total 163 patients) have showed the expected good prognosis, and the 7 cancer-specific deaths have been in patients with advanced disease (Stage III or IV, TNM staging), and all patients were > 55 y at diagnosis. However 3 PTC patients with advanced disease remain well following radical surgery and radiation therapy—the 7 year old with lung metastases, and the 2 adults with intratracheal tumours. Hürthle cell and medullary thyroid cancers have proved more malignant, and again early cancer deaths were associated with advanced disease. Anaplastic cancer had a high mortality, but currently 3 of the 9 patients survive beyond 12 months.

Table 1. Clinical data for thyroid cancer patients—gender and age distribution, and early outcome results

Variables	Papillary	Follicular	Hürthle	Anaplastic	Medullary
Gender					
Female (F)	91	27	14	6	8
Male (M)	39	6	7	3	4
F/M Ratio	2.3	4.5	2.0	2.0	2.0
Median age in years	48	48	64	75	44
(Range)	(7–82)	(16–86)	(36–81)	(50–81)	(17-82)
Residual disease*	7	1	2		1
Cancer-specific deaths to date	4	3	3	6	3
(%)	(3)	(9)	(14)	(66)	(25)
Survival in months	36,36,48,82	22,28,72	3,4,80	1,3,3,5,7,14	4,38,70

*Residual disease: PTC – 3 local, 3 lung 2⁰, 1 brain 2⁰

FTC – 1 lung 2⁰ HTC – 2 local

Medullary – 1 local and lung 2⁰

PTC=Papillary thyroid cancers; FTC=Follicular thyroid cancers; HTC=Hürthle cell thyroid cancers.

Primary thyroid lymphoma patient data (subject of a previous report from this unit) is not shown in Table 1, and all 7 patients were female with a median age of 59y (range 21–83).⁷

Metastasis presenting as a thyroid nodule is rare, and neither patient in our series had a previously diagnosed primary tumour. One patient had primary lung cancer, and the remaining patient presented with a bizarre clinical manifestation—thyrotoxicosis due to a 'metastatic carcinoma-associated destructive thyroiditis'. Initially subacute thyroiditis was diagnosed but fine needle cytology showed papillary cancer with much associated necrosis in both thyroid and cervical node biopsies. The papillary cancer subsequently proved to be of non-thyroid origin, and the patient died of adenocarcinoma of the lower third of the oesophagus.

Discussion

The distribution of the different histological types of thyroid malignancy in our study is similar to reported for other countries. Most tumours were of follicular cell origin with differentiated thyroid cancer (DTC) making up the bulk of our series with more than 70% being papillary thyroid cancers (PTC). The percentage PTC will be an underestimate of the true number of papillary cancers as small cancers <1 cm, often referred to as micro-papillary cancers (mPC), would not have been referred by surgical colleagues for post-operative radiation treatment.

Careful histological examination of thyroidectomy specimens from patients with benign thyroid disease has led to reports of 7.5–10% incidence of incidental thyroid malignancies—usually small papillary tumours. ¹² Our present series includes a small number of such tumours. It seems likely that the increasing incidence of thyroid cancer in New Zealand and in other countries may in part be due to the increased recognition of mPC. ¹³

Follicular thyroid cancers have been the second commonest malignancy—18% of the differentiated thyroid cancers (DTC), and Hürthle cell cancers made up 11% of DTC in our series and this is higher than previously reported. In older reports, however, Hürthle cell cancers were included with follicular cancers. Medullary cancers made up 6% of all tumours, and this is within the previously reported 5-10%. Anaplastic thyroid cancer was relatively rare (4%)—cf reported 2–5%. Two DTC arose in thyroglossal remnants, and such tumours are usually papillary cancers.

The pathological classification of thyroid malignancies has changed over the years and then-current WHO criteria were used. In older series some differentiated thyroid cancers were described as being of mixed papillary/follicular type, and currently most of these tumours are classified as follicular variants of papillary thyroid cancer. ¹⁶ Hürthle cell (large cells showing acidophilic staining due to high mitochondrial content), or oncocytic cancers, are probably best classified separate from follicular cancers as these tumours behave more aggressively, have a greater tendency to metastasise early to lymph nodes, and are less likely to concentrate radioiodine. ¹⁷

One patient had a mixed papillary-medullary cancer, which although rare has been well-documented. ¹⁸ It remains uncertain whether this is 'collision' of one tumour by another of different cell origin (follicular or C cell), or cancers from a common stem cell. However our series also included a second patient with dual pathology—new papillary cancer, and medullary cancer diagnosed 18 years earlier in Eastern Europe by lymph node biopsy. The two primary tumours were spatially separate in the same lobe, and diagnosed asynchronously.

The female incidence was more than twice the male for all types of primary thyroid malignancies in our series, but it is important however to remember that benign disease is much more common in females. Many patients with thyroid cancer have antecedent benign thyroid disease, and this can cause delays in diagnosis especially in older females with long-standing goitre. In young adults, papillary cancer is the predominant histological type, and in the elderly the number of patients with Hürthle and anaplastic cancers and lymphomas made up an increased proportion of patients. Thyroid cancer in childhood is rare and most are papillary cancers and have a good prognosis, even with nodal and lung metastases. ¹⁹

The latest New Zealand cancer statistics suggest a possible slight excess in Māori females but the number of Māori in our series was small and in line with the largely Caucasian population in the South Island.¹ Our experience differs from a previous report from northern New Zealand where there is a much higher Māori and Pacific Island population.²⁰ Epidemiological studies from the Pacific Islands have shown the world's highest thyroid cancer incidence figures in Polynesian and Melanesian populations (35/100,000 in New Caledonian female Melanesians).^{21,22}

The pathogenesis of thyroid cancer is believed to be due to a combination of genetic and environmental factors, and a family history of thyroid cancer is important when evaluating a patient with a thyroid mass. Most clinicians will be aware that medullary thyroid cancer can be part of the spectrum of familial endocrine neoplasms—MEN type 2, and although our 12 medullary cancer patients all seemed to be sporadic, overseas reports have shown some 20% of medullary cancers to be familial, and often part of MEN 2A. (It should be noted that two MEN 2A families are resident in our

area, but were identified by index cases living elsewhere in New Zealand, and the children have had prophylactic thyroidectomy.)

In contrast, our larger group of 184 patients with differentiated thyroid cancer included five patients with a family history of thyroid cancer (in addition to the mother/son PTC pair, the series included a further young male PTC patient with a history that his mother had had surgery 30 years previously for PTC). It is documented that some 2–5% of papillary thyroid cancers may be familial, and this familial non-medullary thyroid cancer (FNMTC) syndrome is not well known in New Zealand.²³ There are distinct familial thyroid tumour syndromes with a predominance of papillary cancers, and FNMTC is best considered a generic term. Advances in molecular genetics have identified several susceptibility genes, and in future this research should result in clinical advances.^{24,25}

In the present series radiation treatment in childhood has not predisposed to any subsequent thyroid cancers, and it seems unlikely that New Zealand radioiodine fallout from early British nuclear testing in Australia, or more recent French testing in the Pacific have played significant roles. A small number of our patients had received radioiodine therapy for nodular goitre in adulthood, and it is doubtful that this played a significant role—such patients had previously been reported, and controversy continues as to whether ¹³¹I predisposes to subsequent thyroid cancer. ^{26, 27}

Metastases to the thyroid are a very uncommon clinical problem, but are not infrequent in autopsy studies of patients dying of malignant disease. Thyroid nodules due to metastases are rare, and the commonest primary sites are kidney, breast, lung, and melanoma but other sites including oesophagus have been reported. In some patients, the primary tumour is unknown (as in our 2 patients), or the thyroid nodule may be the first manifestation of metastasis following treatment of the primary tumour months or years earlier, and the prognosis remains that of the primary tumour. Destructive thyroiditis associated with thyroid metastases causing release of thyroid hormone and thyrotoxicosis is very rare, and has been recently reviewed.

The optimal surgical treatment of thyroid cancer remains a subject of debate, and in this study no attempt was made to analyse the surgical procedures in the public and private hospitals, or the post-operative radiation treatment. There is a worldwide trend to total thyroidectomy followed by radioiodine ablation of thyroid remnants for all differentiated thyroid cancers except for micropapillary cancers. ^{28,29}

Following thyroid ablation, thyroxine 'suppression therapy' is important—in highrisk patients keeping TSH <0.1. In such patients serum thyroglobulin levels should be very low, and if they are subsequently found to be elevated, then imaging investigations are important to detect recurrence. Recent consensus guidelines on the treatment of thyroid cancer have been published recommending management by multidisciplinary teams. ^{30, 31}

Our short-term outcome results (see Table 1) show trends consistent with large series with long-term follow-up. Most patients with DTC remain clinically well, and the patients who have since died all had advanced disease (Stage III or IV, TNM staging) and were >55 y. These preliminary outcome findings are consistent with our previous clinical experience—an audit of our thyroid cancer-specific deaths since 1984 showed

no DTC patient <45 y had died, and all but one patient had advanced disease—unpublished data.

In the present study, outcome in the elderly was much worse. This high DTC mortality rate in the elderly has also been documented in New Zealand thyroid cancer statistics which show a >4-fold increase in mortality in the elderly, but these national overall figures would also include anaplastic cancers which largely occur in this age group. Anaplastic thyroid cancer is highly malignant with median survival <6 mo, but some of our patients have survived >12 mo. Medullary cancer has an intermediate prognosis between DTC and anaplastic cancer, and early cancer deaths occurred. 22

The present study reports the thyroid malignancies occurring in the northern half of the South Island and has provided interesting clinical data. A New Zealand multicentre study with long-term follow-up is needed to provide statistically significant outcome information. In the future, earlier diagnosis by modern imaging techniques and fine needle aspiration cytology should reduce the number of patients presenting with advanced and incurable disease. Advances in molecular biology should lead to better understanding of genetic factors, improved diagnostic techniques and new treatments for metastatic disease.

Competing interests: None known.

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Acknowledgements: This study has been possible with the assistance of surgeons RW Robertson, B Dijkstra; oncologists AS Abdelaal and I Ward; and anatomical pathologist Dr LA Hunter and colleagues. The authors acknowledge the assistance of the Nuclear Medicine secretarial staff, and in particular Bridget Ginley for the data base analysis and manuscript.

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THE NEW ZEALAND MEDICAL JOURNAL



Journal of the New Zealand Medical Association

An audit of colon cancer data on the New Zealand Cancer Registry

Ruth Cunningham, Diana Sarfati, Sarah Hill, Diane Kenwright

Abstract

Aims This study aims to assess the reliability of New Zealand Cancer Registry data on colon cancer.

Methods Data from a review of the clinical records of 642 people diagnosed with colon cancer between 1996 and 2003 were used to audit the data held on these individuals by the New Zealand Cancer Registry (NZCR). The record review data were treated as the "gold standard".

Results Age at diagnosis (measured in years) recorded by NZCR was 96% accurate, and date of diagnosis was within 6 weeks of the clinical date of diagnosis in more than 97% of cases. Overall tumour site was recorded with more than 95% accuracy, with 86% accuracy for tumour sub-site within the colon. Tumour grade was only recorded consistently by the NZCR from 1999 onwards, from which time the NZCR was 83% accurate for tumour grade. Tumour stage was the least accurate variable studied, with 80% accuracy. The NZCR data quality improved over the period of this study.

Conclusions The accuracy of the NZCR appears to be similar to that found in comparable audits of cancer registries, with stage being the hardest variable for registries to collect accurate information on. NZCR data could be improved by improving the quality of information provided to the registry.

Cancer registries have a vital role in cancer control. The New Zealand Cancer Control Strategy¹ has as one of its six goals improving the effectiveness of cancer control through research and surveillance, recognising the central role of information in cancer control. The New Zealand Cancer Registry (NZCR) is a population-based register of all primary malignancies diagnosed in New Zealand (excluding basal and squamous cell skin cancers), and is the primary source of information on cancer incidence in New Zealand.

The International Agency for Research on Cancer (IARC) has identified five main areas of quality to be considered in assessing cancer registries: completeness of cover, completeness of detail, accuracy of detail, accuracy of reporting, and accuracy of interpretation.²

Two studies in New Zealand have assessed the completeness of coverage of the NZCR. Dockerty et al³ looked at the accuracy and completeness of child cancer registrations between 1990 and 1993 using data from the Children's Cancer Registry and hospital admissions and discharges, and found that the NZCR ascertained 97% of cases of childhood cancer over this period, but nearly 10% of cases reported by the NZCR were not in fact confirmed as incident cases of childhood cancer.

A recent audit of lung cancer treatment in Auckland and Northland used regional clinical databases to find additional cases of lung cancer beyond those known to the NZCR, and found that 66 out of 565 cases meeting the eligibility criteria for the study were not known to the NZCR.⁴

Internationally, reviews of medical records have been used as a gold standard against which to audit cancer registry data accuracy, ^{5–11} although it is also possible to use clinical databases, such as were used by Stevens et al to review the accuracy of lung cancer data.⁴

The objective of this audit was to compare the data accuracy of the NZCR against data extracted from the clinical records of 642 people registered with colon cancer between 1 January 1996 and 31 December 2003 as part of a study of Māori /non-Māori colon cancer survival differences. We did not assess the completeness of cover of the NZCR colon cancer data as no suitable dataset for comparison could be readily accessed; neither did we examine completeness of registry detail as this is more appropriately assessed internally by cancer registries.

Approval for this study was granted by the New Zealand Multi-Region Ethics Committee.

Methods

The New Zealand Cancer Registry is a population-based register of all primary malignancies diagnosed in New Zealand. New cancer diagnoses are reported to the Registry mainly by laboratories, which are required by the Cancer Registry Act 1993 to send copies of pathology reports diagnosing cancer. A small proportion of cancer registrations are derived from hospital discharge reports (public and private), death certificates, and coroners' reports.

The NZCR system was upgraded in 2001, with the new database going live in December 2001, at which time data from 1999 and 2000 were still being coded. Data from 1999 onwards are coded using the updated system, which has an increased number of fields and more complete details of cancer stage and morphology (personal communication, S Hanna, 2007). NZCR data are entered by trained coders who specialise in particular cancer sites.

This audit used detailed clinical record data collected for a separate study on colon cancer survival. For the record review, incident cases of colon cancer were identified from the New Zealand Cancer Registry. All eligible Māori cases and a randomly sampled equal number of non-Māori cases were included in the study sample.

The final sample meeting the eligibility criteria (see Figure 1) and with data available included 308 Māori and 334 non-Māori New Zealanders with colon cancer.

Pathology reports were obtained and reviewed for all study patients. Clinical data were obtained from both public hospital and private specialists' records by one of the authors (SH). Data extraction was carried out according to standardised criteria. All data were double-entered and discrepancies were checked.

NZCR data were checked against clinical record data for the same individuals. Clinical records were regarded as a "gold standard"—that is they were regarded as the definitive benchmark against which registry data could be checked for accuracy. Data were analysed using Stata version 10. 12

Discrepancies between the NZCR and hospital record were examined for the following variables: age at diagnosis, sex, date of diagnosis, tumour site within the body, site within the colon, and tumour grade and stage.

The percentage of discrepancies between the record and NZCR datasets are presented as estimates for the total population with colon cancer in order to give an indication of the overall accuracy of the data on colon cancer held by the NZCR, and for the Māori and non-Māori samples combined (raw data).

Population estimates were generated by weighting the data for Māori and non-Māori samples according to the proportion of total colon cancer notifications represented by each ethnic group between 1996 and 2003.

Figure 1. Eligibility criteria

Study Eligibility Criteria

- newly diagnosed cancer of the colon registered between 1 January 1996 and
 31 December 2003
- primary tumour site in the colon: ICD10-AM site codes C18-C19, not including C18.1 (appendix)
- no previous diagnosis of colon cancer
- morphology consistent with or specific to adenocarcinoma: (ICD-O morphology codes 8000, 8010, 8020, 8021, 8050, 8140, 8144, 8145, 8210, 8211, 8260, 8261, 8262, 8263, 8470, 8471, 8472, 8473, 8480, 8481, and 8490)
- · aged 25 years or over at diagnosis
- · usually resident in New Zealand
- diagnosis made prior to death

In some cases, variables were assigned differently by NZCR and in record review. Table 1 sets out the different methods used to assign each variable, and any methods used in this study to facilitate comparison of the two datasets.

Table 1. Differences in methods of assigning variables between datasets

Variable	NZCR	Clinical record	Method for dealing with differences
Age at diagnosis	See date of diagnosis. Date of birth recorded under NHI	See date of diagnosis. Date of birth recorded under NHI	nil
Sex	As recorded under NHI	As recorded under NHI	nil
Date of diagnosis	Date of pathology report, or date of hospital admission, or date of death (if post-mortem diagnosis)	Clinical date of diagnosis (date cancer confirmed)	Accuracy to within 6 weeks reported (exact correlation not expected because of different definitions)
Tumour site within body	Based on pathology report or hospital discharge data	Based on all available information including investigation results, examination findings and surgical and pathology reports	nil
Tumour site in colon	Based on pathology report (pathologist relies on clinical information provided by the requesting clinician). Categories based on ICD-9 and ICD-10AM	Based on all available information including investigation results, examination findings and surgical and pathology reports. Categories based on ICD-	Categories overlapping (used by NZCR) and synchronous (used in record review) excluded from analysis as not comparable

		10AM, but also including	
		synchronous category	
Tumour grade	Based on pathology report, only recorded reliably from 1999 (prior to this recorded in free-text field), recorded as unknown if no grade stated on report, least differentiated grade recorded	Based on pathology report, recorded as moderate if no grade stated* (47 cases), least differentiated grade recorded	Those registered prior to 1999 and those with no grade stated on the report were excluded from comparisons
Tumour stage/	SEER summary staging system based on	TNM staging (pathological)	Record data converted to SEER
extent of disease	pathology report (principally) and any	based on all available clinical	summary staging (NB required
	investigations within four months of	data, including all	recoding from pathology reports
	diagnosis (investigation reports not reliably	investigations within four	as the systems do not map one
	received by NZCR), assigned according to	months of diagnosis, assigned	to one)
	the furthest extent of known involvement,	according to the furthest extent	
	reported as 'extent of disease'	of known involvement	

^{*}Based on pathologist's advice that pathologists may only make note of exceptional grade (well and poorl;y differentiated cancers) in their reporting.

Results

Table 2 shows the discrepancies between the NZCR and record data for each of the six fields examined. Table 3 shows the trends over time in the quality of cancer registry data for the main variables examined.

There was good agreement between the datasets with respect to age at diagnosis (measured in years), sex, and date of diagnosis (within 6 weeks). Agreement was less complete for the other variables examined.

Table 2. Discrepancies between cancer registry and clinical record

Field	Population estimate (weighted)^ % discrepancies	No. records with data available (raw data)	No. discrepancies
Age at diagnosis (years)	3.6%	642	20
Sex	0.6%	642	2
Diagnosis date (exact)*	71.2%	634	436
Diagnosis date within 6 weeks*	2.7%	634	15
Tumour site within body**	4.6%	776	51
Tumour site within colon***	13.6%	600	78
Tumour grade (1999 onwards)****	17.4%	420	78
Extent of disease (stage)	19.7%	642	122

^{*}Excluding those with derived diagnosis date in record data (n=8); **Includes all cancers in original sample reported by the NZCR to be colon cancer, of which 51 were not in fact confirmed colon cancer primaries. A further 83 of the 776 were excluded from the final study sample for other reasons; ***Excluding synchronous and overlapping categories (n=42); ****Excluding grade not stated on pathology report, no field for tumour grade prior to 1999; ^Weight=proportion of ethnic group in total NZCR colon cancer population. Māori weight=0.0256; Non-Māori weight=0.9744.

Table 3. Trends over time in discrepancies

Field	Population estimate (weighted)^ % discrepancies	No. records with data available	No. discrepancies
	, auser epanieres	(raw data)	uiserepuneres
Tumour site within body ** (1996-1998)	6.3%	274	21
Tumour site within body (1999-2001)	3.3%	302	16
Tumour site within body (2002-2003)	3.8%	200	15
Tumour site in colon*** (1996-1998)	15.0%	222	26
Tumour site in colon*** (1999-2001)	11.4%	152	30
Tumour site in colon*** (2002-2003)	10.1%	168	22
Tumour grade**** (1999-2001)	11.2%	238	29
Tumour grade**** (2002-2003)	19.1%	162	29
Extent of disease (1996-1998)	26.6%	222	61
Extent of disease (1999-2001)	17.3%	252	38
Extent of disease (2002-2003)	11.5%	168	23

^{**}Includes all those reported by the NZCR to be colon cancer; ***Excluding synchronous and overlapping categories; ****Excluding grade not stated on report; ^Weight=proportion of ethnic group in total NZCR colon cancer population. Māori weight=0.0256; Non-Māori weight=0.9744.

Tumour site—Of the 776 patients whose records were examined (all reported by the NZCR to have colon cancer), 51 (7%) did not in fact have a diagnosis of colon cancer. In 19 cases, the primary tumour was not located, in 29 cases the tumour was in the rectum rather than the colon, and there was one case in each of the oesophagus, small bowel, and stomach. A further 83 cases were not eligible for the study for other reasons (principally lack of histological diagnosis), resulting in a final sample of 642.

Tumour site within colon—There was a discrepancy in tumour site within the colon between the two datasets in approximately 13% of cases (once the categories synchronous and overlapping had been excluded), and this remained similar over the study period. Table 4 shows the actual discrepancies found between the datasets. Most of the miscoding of tumour site is miscoding to an adjacent site (between right and left colon, between left colon and rectosigmoid junction).

Tumour grade—Following the upgrade of the NZCR in 2001 (affecting data from 1999), grade information was 83% accurate. Table 5 shows the actual discrepancies between the datasets after exclusion of those diagnosed prior to 1999. The most common source of discrepancy was where NZCR assigned an unknown grade, while the record review identified a grade.

In other cases, different grades were reported by the NZCR and record data extraction. This most often occurred when the pathology report noted more than one grade in different parts of the tumour, in which case the record review recorded the higher grade (less differentiated) while the NZCR often recorded the lower grade.

Table 4. Comparison of record and registry data for cancer site*

Tumour site:		Tumour site: clinical record					
cancer registry	R colon	R colon L colon Rectosigmoid Synchronous unknown Tota					
R colon**	248	11	0	12	0	271	
L colon	12	206	38	15	0	271	
Rectosigmoid	0	10	62	3	0	75	
Overlapping***	4	2	1	5	0	12	
unknown	1	5	1	0	6	13	
Total	265	234	102	35	6	642	

^{*}Bold numbers indicate the number of records with agreement between the two datasets, while the other numbers indicate records with discrepancies; **R(ight) colon: caecum, ascending colon, hepatic flexure, transverse colon; L(eft) colon: splenic flexure, descending colon, sigmoid colon; ***This category was not used in record review.;

Table 5. Comparison of record and registry data for tumour grade (excluding no grade stated, and prior to 1999)

Tumour grade: cancer	Tumour grade: clinical record				
registry	Well	Moderately	Poorly	Unknown	Total
	differentiated	differentiated	differentiated		
Well differentiated	32	3	2	0	37
Moderately differentiated	3	243	12	0	258
Poorly differentiated	0	3	64	0	67
Undifferentiated*	0	0	1	0	1
unknown	4	43	7	3	57
Total	39	292	86	3	420

^{*}This category was not used in record review.

Table 6. Comparison of record and registry data for extent of disease 1996-1998

Extent of disease: cancer		Extent of disease: clinical record				
registry	1	1 2 3 5				
	Localised	Regional spread*	Metastatic spread	Unknown		
1 Localised	37	14	0	0	51	
2 Regional spread*	11	88	15	0	114	
3 Metastatic spread	0	7	35	0	42	
5 unknown	6	4	4	1	15	
Total	54	113	54	1	222	

^{*}Direct extension or lymph node involvement.

Tumour stage (extent of disease)—The proportion of discrepancies between the two datasets for tumour extent of disease was approximately 20% and this reduced over the time period of the study. Tables 6 and 7 show that there were two main areas of discrepancies: between localised and regional disease (with discrepancies in both directions) and between regional and advanced disease (with the NZCR showing a less advanced extent than the clinical record).

Table 7. Comparison of record and registry data for extent of disease 1999–2003

Extent of disease: registry	Extent of disease: clinical record					
	В	C	D	E	F	Total
	Localised	Direct regional	Lymph node	Metastatic	Unknown	
		spread	involvement	spread		
B Localised	83	11	1	1	0	96
C Direct regional spread	11	58	0	0	0	69
D Lymph node involvement	1	2	125	14	0	142
E Metastatic spread	0	4	6	86	0	96
F unknown	3	0	2	5	7	17
Total	98	75	134	106	7	420

Discussion

New Zealand Cancer Registry data is used for wide a range of applications, including research, policymaking, and health service planning. Any such work depends for its accuracy on the quality of NZCR data, and so it is important to know that data provided by the NZCR are reliable in terms of demographic and diagnostic details.

This study found that cancer registrations for colon cancer on the NZCR were highly accurate with respect to demographic details, but less so for details relating the site, grade and stage of the tumour. The accuracy of the NZCR appears to be similar to that found in comparable audits of cancer registries in the United States, the United Kingdom, and the Netherlands,^{5–11} with stage being the hardest variable for registries to collect accurately.

The recent audit of lung cancer registrations in New Zealand conducted by Stevens et al also found that stage was the least accurate variable. Encouragingly, NZCR data improved following changes to the registry in 2001.

The key limitation of this study is that it assumes that perfect information is captured by the clinical record, which is of course not the case. Identifying clinical and pathological inaccuracies recorded in clinical records is beyond the scope of this study. However, such errors will be largely consistently recorded by both record review and the NZCR because data for the NZCR are usually drawn either directly from clinical sources (e.g. the pathology report) or from data sources which are extracted from clinical record data (e.g. hospital discharge data).

It is also assumed that data extracted from clinical records are recorded without errors. All data were extracted by the same individual according to pre-designated rules, and were double entered to avoid data-entry errors. Original pathology reports were also referred to in order that particular discrepancies could be better understood. Both of these methods help to limit the possibility of errors arising in the clinical record data.

Some discrepancies were to be expected given the different ways in which variables were defined in the two datasets. This was particularly the case for date of diagnosis, where completely different definitions were used, and this difference also affected the comparability of age at diagnosis.

Other discrepancies found relate to the nature of information available to the NZCR. NZCR coding of tumour site (and most other information) relies almost solely on pathology reports. Pathologists rely in turn on surgeons for an indication of tumour

site to be noted with the specimen, as it can be difficult to accurately site a segment of resected colon. For this reason pathology reports may not give an accurate reflection of tumour site. Data drawn from clinical records included information from operation notes and scan reports, providing a better characterisation of tumour site. The different sources of data may explain most of the discrepancies seen. The best way to overcome this problem is through improving the quality of reporting to the NZCR.

The Australasian College of Pathologists is currently developing a *pro forma* for synoptic reporting of colorectal cancer specimens (a standardised template for pathology reporting), which if adopted will provide more consistent information for NZCR coders. A *pro forma* for breast cancer specimen reporting has been used since the introduction of breast cancer screening in New Zealand. Communication with surgeons about the need for adequate clinical details on pathology request forms may also help to improve the quality of information available to the NZCR.

Further discrepancies relate to the systems used by the NZCR, particularly in relation to staging. The SEER summary staging system¹³ is used by the NZCR. In contrast, the TNM system¹⁴ is frequently used by pathologists and other clinicians. TNM is a clinical staging system which categorises cancer spread according to three characteristics: the primary tumour (T), involvement of regional lymph nodes (N) and presence or absence of distant metastases (M). The TNM and summary stage systems are not directly comparable.

As can be seen from Table 8, the distinction between localised and regional disease in the SEER system divides the T3N0M0 (IIa) category in two for colon cancer, with some cancers in this category counting as localised and some as regionally advanced. Problems with the use of summary staging systems have been noted by other authors, and confusion over the application of the local/regional distinction for colon cancer in the SEER system is reported by NZCR coders (personal communication, C Bainbridge, 2007), which may explain the discrepancies between localised and regional disease found between the clinical record and NZCR datasets.

The TNM and SEER summary staging systems have different strengths. The SEER system is specifically designed for use by cancer registry coders. It has the advantage of being less complex than other staging systems and relatively stable over time. The TNM system on the other hand is a dynamic system designed for use by clinicians. TNM stage is assigned based on clinical and pathological observations, and is intended to give good prognostic information to clinicians.

Table 8. SEER summary stage and equivalent TNM stage for colon cancer*

SEER summary stage	Description	Equivalent TNM stage
Localised	Invasive tumour confined to colon. Includes tumour	Stage I and IIa:
	extension through muscularis propria and subserosal	T1-T3
	tissue, but not serosal surface.	N0
		M0
Regional	Tumour extension outside colon and/or invasion of	Stage IIa and IIb and III:
	regional lymph nodes. Includes local tumour	T3–T4 / Any N
	extension into serosal surface, pericolic or	Any T / N1,2
	mesenteric fat **	M0
Distant	Tumour spread to distant organs or lymph nodes.	Stage IV:
		Any T
		Any N
		M1

^{*}From SEER Program Coding and Staging Manual 2007¹⁵; **Also adjacent tissues/connective tissue/fat, mesentery, mesocolon, retroperitoneal fat, gastrocolic ligament, greater omentum and any other abdominal or pelvic organs.

The NZCR is reliant on pathologists recording TNM stage on pathology reports if it is to collect information on TNM stage. However the problems with assigning SEER summary stage in colon cancer, and the problems for clinicians in interpreting data which use the SEER system, mean that the TNM stage should also be recorded by the NZCR whenever possible.

The UK guidelines for colorectal cancer management recommend that TNM stage is always recorded on colorectal pathology reports. 16 If such a requirement was adopted in New Zealand it would be much easier for the NZCR to reliably collect this information. In the United States a collaborative staging system is being developed specifically to overcome problems of incompatibility between staging systems, ¹⁷ and the possibility of using this system in New Zealand could be explored.

Cancer registry data is the main source of information on the incidence of one of New Zealand's major causes of death and disability. It is therefore very important that the quality of the data provided by the NZCR is monitored and improved.

New Zealand is currently in the process of developing extensions and improvements to cancer data collections, which will provide an opportunity to address some of the issues raised here around the flow of information from clinicians to the registry, as well as ensuring the appropriate systems for collecting information such as stage are used. The recently announced intention to introduce colorectal cancer screening is also likely to provide an impetus to improve colorectal cancer data collection. Competing interests: None known.

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Acknowledgements: The authors thank Susan Hanna and Christine Bainbridge from NZHIS for their helpful advice on the workings of the NZCR, Emma Britton for assistance in obtaining pathology reports and checking data, and the members of the team involved in designing and carrying out the Ethnic Disparities in Colon Cancer Survival study from which data were drawn for this paper.

The members of the study team are Diana Sarfati, Sarah Hill, Gordon Purdie, Bridget Robson, Donna Cormack, Tony Blakely, Elizabeth Dennett, and Kevin Dew. The authors also acknowledge the Cancer Society of New Zealand for providing funding for the above study (grant 05/16).

The Ministry of Health provided funding for a report on New Zealand Cancer Registry data quality on which this paper is based (the views expressed in this paper do not necessarily reflect those of the Ministry of Health). The Australasian Faculty of Public Health Medicine training programme provided a salary subsidy for Ruth Cunningham.

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Journal of the New Zealand Medical Association

The value of voluntary morbidity and mortality meetings at a New Zealand metropolitan hospital

Magdalena Sakowska, Saxon Connor

Abstract

Aim To assess the value and outcomes of contemporary, voluntary meetings reviewing the morbidity and mortality among surgical patients presenting at a New Zealand metropolitan hospital.

Methods Data on morbidity and mortality were prospectively collected and analysed over a two year period (March 2005–August 2007) from weekly departmental meetings. Patients were discussed on a patient by patient basis; the details and outcomes of this were formally constituted and documented into a database. Actual mortality numbers and unplanned returns to theatre were obtained from clinical coding. Consultant attendance was documented

Results Morbidity and mortality was recorded and discussed in 900 patients (6.5% of total admissions). Morbidity was discussed in 738 patients (incidence 5%); 190 (1.4%) deaths were discussed. Only 58% of unplanned returns to theatre and 62% of mortality recorded by clinical coding were discussed. However 54% of unplanned returns to theatre and 35% of mortality that were discussed were not recorded by clinical coding. It was felt that the clinical pathway had been appropriate in 88% and 91% of discussed morbidity and mortality, respectively. Over time, there was no significant change in consultant attendance (7/13 at 6 months vs 7/13 at 2 years, p=NS) and no trend in the median number of patients discussed per month.

Conclusions In the setting of a voluntary morbidity and mortality meeting only 12% and 8% of patients discussed, respectively, resulted in further action being initiated. Despite there being significant under-reporting of both morbidity and mortality, this format identified data that had previously been missed by hospital coding. If value is gained from the morbidity and mortality meetings, it is not reflected in consultant attendance or in the number of patients submitted for discussion as these did not change over time.

Surgical audit and peer review are important strategies in maintaining highest standards in surgical care, and are needed wherever improvements in patient care and outcomes are sought. ¹ Although there is no government mandate requiring New Zealand (NZ) hospitals to participate in clinical audits, ² the Royal Australasian College of Surgeons (RACS) recommends that surgical audits be part of a surgeon's everyday practice. ¹ Indeed, an Australian Audit of Surgical Mortality, pioneered in Western Australia, is currently being rolled out bi-nationally. ²

Educational opportunities resulting from surgical audits are not solely limited to identifying individual or departmental underperformance. Educational opportunities can also include gaining knowledge of new technologies and procedures, or focusing educational meetings to topics where up to date evidence-based practice is unclear.

At a management level, audits can help identify hospital system inefficiencies and optimise the use of limited resources available for the provision of surgical services, or may identify "systems failure" so that change can be directed to the appropriate hospital authorities. Furthermore, surgical audits and peer review are essential components of Continuing Professional Development; when presented appropriately, audit and feedback can be effective in improving professional practice.³

Prior to March 2005, audit at the Department of Surgery, Christchurch Public Hospital (CPH) consisted of a yearly review of an individual consultant's practice with selected patients being presented for discussion. The lack of contemporary review meant that little or no meaningful discussion was achieved, junior staff who had been involved in the care had subsequently left the department and no outcome of the review was achieved. Thus a decision was made to change to a voluntary weekly morbidity and mortality meeting.

The aim of this study is to assess the value and outcomes of these voluntary meetings.

Methods

Morbidity and mortality meetings are held at the Department of Surgery (general and vascular), CPH, on an ongoing, weekly basis during protected time and within an ethical and confidential framework. Attendance, although documented (for consultants), is voluntary with consultants through to fourth year medical students being encouraged to attend. After discussion as a department, it was decided that a target consultant attendance would be 75% of meetings (allowing for holidays, conference leave and clashes with other commitments, surgeons with part-time appointments), while attendance above 60% would represent an acceptable level of attendance.

Prior to the meeting, patients to be discussed are de-identified and entered into a database (Table 1). Patients are then discussed on a patient by patient basis. Following the meeting, the details and outcomes are formally constituted and documented into the database by the morbidity and mortality chairperson (SC). Surgical adverse event monitoring is limited, as recommended.⁴ Appendicectomy histology is obtained weekly from the pathology department. To validate the accuracy of reported data on actual unplanned returns to theatre and mortality, additional data was obtained independently from the clinical coding unit.

Nominal data are presented here with percentages in parentheses and analysed where appropriate with Chi-squared test or Fisher-exact test. Continuous data is presented as median (range) and analysed with Mann Whitney U. Attendance is analysed by a cumulative failure rate (CUSUM). P value is considered significant if <0.05.

Results

A total of 13,755 patients were admitted under the care of the Department of Surgery during the audit period (March 2005–August 2007), of which, 4,426 (32.2%) were elective patients (Table 2). Morbidity and mortality was voluntarily recorded and subsequently discussed in 900 (6.5%) patients (Table 2). In five (0.5%) patients, the type of admission (elective versus acute) was not recorded. The median age was 69.5 years (range 15–96 years).

Table 1. Data and outcomes recorded at weekly morbidity and mortality meetings

Variable	Data
Patient number	
Age	
Consultant	
Admission type	Elective/Acute
Operation	Yes/No
Subspecialty	
Mortality	Yes/No
Expected death	Yes/No
Cause of mortality	Technical (surgical)
	Systemic (non surgical) e.g. pneumonia, myocardial infarction
	Disease process
	Systems failure
Morbidity	Yes/No
Type morbidity	Surgical site complication (wound complication, postoperative
	bleed, anastomotic leak, bile duct injury)
	Diagnostic error
	System failure
	Pulmonary embolus
	Myocardial infarction
	Systemic (non-surgical) complication
	Complication associated with disease process
Unplanned return to theatre	Yes/No
Outcome	No action required, clinical pathway appropriate
	Action to be implemented at local level
	Letter to risk management/other departments
Was a coroner's post mortem	Yes/No
requested	
Was a coroner's/hospital post mortem	Yes/No
performed	
Did the meeting feel a	Yes/No
coroner's/hospital post mortem was	
indicated	

Table 2. Summary of morbidity and mortality data according to admission type for the Dept of General Surgery, Christchurch Hospital, March 2005–August 2007 (note that in five patients discussed, the type of admission [elective versus acute] was not recorded)

Admission type	Admissions	Operations	Morbidity	Mortality
Elective	4426 (32%)	3665 (51%)	380 (9%)	36 (0.8%)
Acute	9329 (68%)	3571 (49%)	354 (4%)	153 (1.7%)
Total	13,755	7236	738 (5%)	190 (1.4%)

Mortality was reported in 190 patients (1.4% of all admissions). The median age of those who died was 78 years (range 19–96 years). 100 (53%) of these 190 patients underwent surgery, 7 (4%) of whom had an unplanned return to theatre (2 of these 7 were the result of a surgical (technical) complication). Of the 116 deaths as a result of

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716

URL: http://www.nzma.org.nz/journal/121-1279/3190/

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disease process, 65 (34%) deaths were regarded by the attending clinicians as expected.

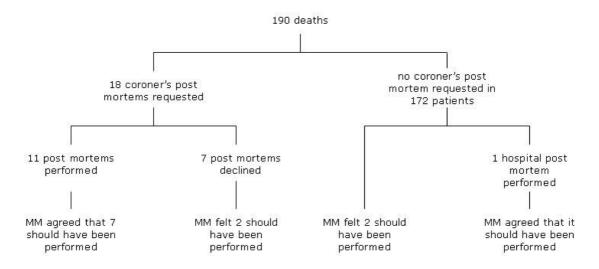
Causes for mortality are summarised in Table 3. A coroner's post mortem was requested in 18 patients but only performed in 11 (Figure 1).

Comparison to hospital coding showed 182 deaths had been coded under general surgery during the same time period. An analysis of individual patients revealed that 113 (62%) of those recorded by hospital coding were actually discussed at the morbidity and mortality meeting. A further 11 patients did not have their national health index (NHI) recorded and it is not clear if these patient deaths were correctly coded. Excluding these and one duplicate entry, 66 patients (35% of those discussed) were identified from the audit meeting who were not recorded by hospital coding as a departmental mortality.

Table 3. Summary of all cause morbidity and mortality for patients discussed at the department of surgery morbidity and mortality meetings held between March 2005–August 2007 (note that the sum of all cause mortality or morbidity will exceed 100% as some patients may have suffered more than one type of complication)

Variables	Morbidity	Mortality
Technical (surgical)	388 (53%)	15 (8%)
Systemic (non-surgical)	253 (34%)	59 (31%)
Disease process	162 (22%)	116 (61%)
Systems failure	47 (6%)	5 (3%)

Figure 1. A summary of mortality management showing where post mortems were requested and performed and where the morbidity and mortality meeting (MM) discussion felt it was indicated



Regarding outcomes for mortality, in 172 patients (91%) it was felt that the clinical pathway had been appropriate and that no further clinical action was required after the meeting. In the remaining 16 (8%) patients it was recommended that either an action should be implemented at a local level (n=12 (6%)) or letters to risk management/other departments were sent (n=4 (1.5%)). No action was recorded in 2 (1%) patients.

Morbidity was reported in 738 patients (incidence 5%); 380 (51%) of which were elective patients. The median age was 66 years (range 15–96 years) which was younger than for those patients who died (p<0.01). Cause for morbidity are summarised in Table 3 and clinical indicators are summarised in Table 4.

Table 4. Incidence of clinical indicators recorded for the Department of Surgery between March 2005–August 2007

Condition	Morbidity		
Surgical-site complication	135 (18%)		
Postoperative haemorrhage	60 (8%)		
Diagnostic error	40 (5%)		
Anastomotic leak	35		
Bile duct injury	5		
Pulmonary embolus	16 (2%)		
Myocardial infarction	37 (5%)		
Normal appendicectomy	68/618 (11%)		

Percentages indicate the proportion of morbidity (n=737); where omitted, the denominator is not known.

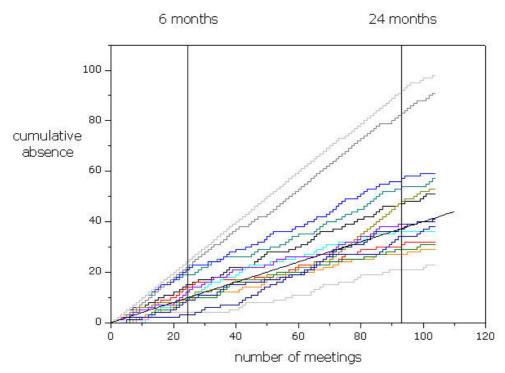
182 (25%) patients were discussed regarding an unplanned return to theatre whereas only 142 were identified by hospital coding during the same time period. A comparison of individual patients revealed that 82 (58%) of those recorded by hospital coding were actually discussed at the morbidity and mortality meeting.

Conversely, 98 patients (54% of those discussed) were identified form the audit meeting who were not recorded by hospital coding as an unplanned return to theatre. In 2 patients, an NHI was not recorded from the meeting and it is unclear whether these were correctly coded or not.

Concerning morbidity, in 648 patients (88%) it was felt that the clinical pathway had been appropriate and that no further clinical action was required after the meeting. In the remaining 87 (12%) patients it was recommended that either an action should be implemented at a local level (n=75 (10%)) or letters to risk management/other departments were sent (n=12 (1%)). No action was recorded in 3 (0.4%) patients.

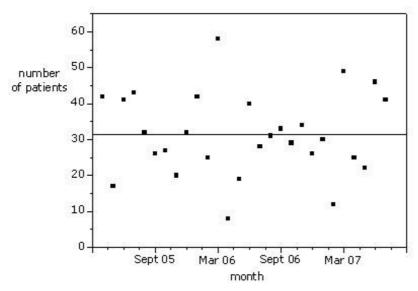
Consultant attendance is summarised as a cumulative absence rate for each individual surgeon by meeting (Figure 2). The total number of patients discussed per month is shown in Figure 3.

Figure 2. CUSUM analysis of consultant attendance at weekly morbidity and mortality meetings (March 2005–August 2007)



Each surgeon is represented as a different coloured line. One meeting equals one event thus public holidays, and days on which meetings did not occur are excluded from the analysis. The agreed acceptable attendance (60%) is indicated by the straight slope. There was no significant change in the number of consultants above this attendance slope over time (7/13 at 6 months (after 24 meetings) vs 7/13 at 2 years (after 92 meetings), p=NS).

Figure 3. Total number of patients discussed per month over the audit period (March 2005-August 2007)



The straight line is the trend line. Elective and acute admission rates have remained static over the analysis period (data not shown).

Discussion

Audit is about continuously improving learning from experience and making appropriate changes, not just about collecting data. Traditionally audits have focused on surgical adverse events, reflecting the underlying assumption that adverse events are the consequence of poor quality healthcare. This is not always the case, as premorbid risk factors also contribute significantly to perioperative morbidity and mortality, regardless of the quality of healthcare received. However, it is important to ensure that the rate of complications locally is in line with current international published morbidity and mortality rates.

Clinical indicators provide a useful way to achieve this by allowing a hospital/department to benchmark itself against other comparable services. Although the current study would suggest that an acceptable performance was achieved^{4,5} it is likely that the incidence of such indicators will be under-estimated. Both the voluntary nature of the reporting system and the global trend towards reducing the length of hospital stay post-surgery, means that delayed complications (particularly non-surgical in origin) will be under-reported as they may not return to the surgical team for treatment.

To try and minimise such under reporting, an institutional policy of formal notification to surgical teams for all patients re-admitted with post-surgical thromboembolisim has been implemented at CPH. Alternatively bile duct injury is over represented due to CPH being a tertiary referral centre. The incidence of normal appendicectomy can however be compared with certainty. Histopathological analysis is carried out on all resected appendices regardless of their macroscopic appearance. The current study reports a rate of 11% of normal appendicectomies. This compares favourably with published results. ^{6,7}

What is not commonly reported from such an audit however, is the result of the outcome of the discussion from the meetings. This study has shown that in 12% of patients discussed, in terms of morbidity, further action resulted.

Although 86% of these could be dealt with at a local level (such as education of junior staff, commission of an evidence-based review, development of a departmental pathway), 14% were regarded by the department to be of a serious enough nature or a systems error that a formal letter was drafted to risk management. A formal review of dosing and recording of intraoperative low molecular weight heparin (after two incidents of double-dosing) is a good example.

Comparison of numbers alone would suggest that the number of unplanned returns to theatre (surrogate marker of most severe surgical morbidity) is mostly discussed at the morbidity and mortality meetings. However, breakdown of individual patients reveals that this is not so.

Firstly, there is significant under-reporting of patients that have an unplanned return to theatre, as only 58% of those coded by the hospital were discussed at the department audit meeting. Furthermore, it appears that hospital coding does not capture a significant proportion of those that are returned to theatre but are discussed at the meetings. This problem arises as a return to theatre is only coded if a patient has

two theatre events within one hospital admission. Those that are discharged and readmitted for further surgical intervention or those that are transferred from another hospital are missed. Therefore, as a direct result of this meeting, a significant amount of missed morbidity has been detected.

To help overcome the problem of patients who meet the criteria for unplanned return to theatre not being discussed at the morbidity and mortality meeting, individual surgeons are sent a letter when a patient is identified as having two operations within the one admission. This letter asks whether the patient met the criteria for an unplanned return to theatre and if this patient has been discussed at the morbidity and mortality meeting.

A similar issue occurs with inpatient mortality. Although 62% of coded departmental mortality is discussed at the meeting, 35% of deaths discussed at the meetings were not coded correctly. This reflects a hospital coding problem, where patients are admitted under another service (or transferred from private) and the death is often not coded to the consultant looking after the patient at time of death. It is, however, encouraging that from 191 deaths discussed at the meeting only 4 patients were identified in whom a post mortem should have been performed when it was not (Figure 1).

What cannot be determined from this study is the value that would have come from discussion of those patients not presented to the morbidity and mortality meeting. This is an important question to be answered by future studies if voluntary methodology is to be pursued.

Audit and feedback can be effective in improving professional practice although the effects are generally small to moderate and more likely to be larger when baseline adherence to recommended practice is low.³ A surrogate marker of the value placed on this meeting by consultants is attendance over time. From the audit's initiation, comparison at 6 months with the 2-year point prevalence, attendance remained unchanged with respect to an agreed acceptable minimum (Figure 2).

For some consultants, other commitment clashes mean that this is unlikely to change and reflect on the value of these meetings. Conversely, the median number of patients discussed per meeting (Figure 3), does not demonstrate an increasing trend from the time the meetings were first implemented. This would suggest that if value is gained from the morbidity and mortality meetings, it is not reflected in the number of patients submitted for discussion.

In similar voluntary mortality audits, consultant participation was 73% and 91% in Western Australia and Scotland, respectively. Both of these audits are well established and have demonstrated a change in surgical practice and an emphasis on the importance of ongoing systematic audit; perhaps with time, and closure of the clinical audit cycle, attendance rates will improve locally. For such meetings to be effective it is important surgeons show a commitment to attendance and participation.

It is concerning that hospital coding seems to be so inaccurate. This may be a reflection of the lack of infrastructure and clinician input into coding of complications. Given New Zealand's population size, there would be scope for a surgical audit to be carried out at a national level, allowing comparison across hospitals and regions, and economising on costly infrastructure required to run such a

process. Indeed, the extension of a bi-national RACS surgical mortality audit, modelled on the successful Western Australian Audit of Surgical Mortality (WAASM), would be welcomed here.

This audit is undertaken for the public good, aiming to identify areas of surgical practice at CPH where unnecessary morbidity and mortality can be minimised. Overall, in 12% of morbidity patients discussed and 8% of mortality, further action was initiated. A voluntary reporting system only identified 58% and 62% of unplanned returns to theatre and mortality respectively.

Conversely, this format identified 54% of unplanned returns to theatre and 35% of mortality that had previously been missed by hospital coding. If value is gained from the morbidity and mortality meetings, it is not reflected in increased consultant attendance or in the number of patients submitted for discussion as these did not change over the audit period.

Competing interests: None known.

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Hospital discharges in New Zealand 1991–2005: changes over time and variation between districts

Antony Raymont

Abstract

Aim This paper describes changes in the rate of hospital discharges in New Zealand between 1991 and 2006, and assesses variation across districts; it contributes to the discussion of the adequacy of the health system.

Methodology Data on public hospital discharges were obtained from the NZ Health Information Service. Diagnostic Related Groups were used to group and weight cases; domiciliary codes were used to assign cases to districts and as an indication of patients' socioeconomic status. The Intervention Ratio was used as a relative measure of national hospital throughput from 1991 to 2005, and of district service volume. The Coefficient of Variation was used as a measure of overall system variation.

Results There has been an increase of 50.5% in weighted discharges from public hospitals between 1991/2 and 2005/6; adjusted for population change the increase is 17.9%. There has been a modest fall in the degree of variation between districts, but in medicine and surgery 24% of district departments appear to have levels of discharge significantly above or below the national average.

Conclusions The intensity of public hospital care to the New Zealand public has increased. Where services are provided at a level above or below the national average, local explanations should be sought and corrective action undertaken if warranted.

All New Zealanders, not least those who work within it, are interested in the adequacy of the public healthcare system. Interest may turn to concern with news reports of individuals who have not received desirable care.

This paper considers hospital discharges as one measure of system adequacy and examines changes in their numbers over time. There is evidence that hospital services are often unevenly distributed¹ and the paper also quantifies district variation in discharge rates across New Zealand.

There have been significant alterations in the New Zealand health system since 1990, including: the introduction of Regional Health Authorities (RHA) in 1993, the Health Funding Authority (HFA) in 1997 and District Health Boards in 2001;² and the implementation of population based funding of regions in 1998³ and of districts in 2002.⁴

In addition, the Government has made a number of short-term investments in elective surgery and has recently announced ongoing increases in funding—major joint replacements (2004); cataract extraction (2005); and general elective surgery (2008).⁵ Each of these interventions created opportunities to modify the level of hospital services and to improve equity between districts.

The Ministry of Health has published "Hospital Throughput" statistics yearly from 1992 to 2003. The present study uses a similar methodology but compares data across the whole period from 1991 to 2006, estimates the level of services adjusting for population increase and aging, and uses a coefficient of variation to assess the overall level of variation. Age, socioeconomic status, and ethnicity are used as partial proxies for need.

Hospital discharges are attributed to departments—medicine, surgery, high-cost, and maternity. The high-cost grouping has been created, following Jackson, to recognise that some conditions require interdisciplinary input; it includes, for example, trauma and transplantation.

Both medicine and surgery include cases for which admission is, in some sense, elective. In medicine, there may be a choice between inpatient and community-based care and, in surgery, the surgical treatment of some conditions may be delayed or other treatment modalities may be substituted. If the level of service is adequate and unnecessary admissions are rare, it would be expected that levels of admission would increase with population need and that, with need accounted for, variation would be minimal.

The provision of public hospital care in New Zealand is the responsibility of District Health Boards (DHBs) who contract for a specific volume of medical and surgical care by specialty. The volume is based partly on historical levels and partly on current needs-analyses. In practice, demand (for example, a bad 'flu season) can lead to some variation from contract. Thus, in principle, the DHB contract determines the volume of medical and surgical admissions and, if variation exists, it reflects resource distribution choices by each DHB.

In contrast, the contract for maternity care is open-ended, determined by the number of pregnancies and the incidence of complications. It would be anticipated that there will be minimal supply-based variation and any differences may be ascribed to factors not considered or to random effects. Similarly, in the high-cost grouping, dominated by trauma, there is little choice about admission and hospitalisation rates can be expected to reflect the incidence of trauma over time and across districts.

Methodology

The hospital discharge data (National Minimum Data Set—NMDS) for 1991–2006 were obtained from the New Zealand Health Information Service. The dataset had been cleaned: non-residents cases and duplicates had been removed; cases involving inter-hospital transfer had been combined; and various algorithms applied to ensure comparability across reporting sites. When the hospital stay was less than 3 hours, and no general or spinal anaesthetic was given, the discharge had been excluded.

Each discharge is assigned to a "Diagnostic Related Group" (DRG). DRGs are designed to group similar cases and each has a weight based on the average cost of providing the service. During the period covered, the DRG coding was revised; data using other versions were re-coded to Australia New Zealand DRG version 3.1.

DRGs involving a procedure were included in surgery and most other DRGs were included in medicine. An additional category, "high-cost," including DRGs requiring multi-specialty input was created. This included admissions for trauma, burns, transplantation, and maxillofacial surgery. The final category, maternity, included DRGs related to midwifery, obstetrics, and neonatal care. The full classification of approximately 700 DRGs is available for inspection. A similar division is used by Jackson and the New Zealand Ministry of Health, although the latter does not distinguish the high-cost group.

The NMDS provides a "domicile code" for each case, corresponding to the "census area unit" (CAU) of the patient's residence. These were used to assign each discharge to a district; each being assigned to the patient's given residential address, not to the site of hospital care. Those admitted away from their own district, either in an emergency when away from home, or for regionally based tertiary care, count towards the level of care provided to the population of their home district.

The NZDep01⁹ is a measure of socioeconomic deprivation, calculated for each CAU, and based on census data. Each domicile code (and, therefore, each case) was assigned to a value of the NZDep01. While an individual's economic status may differ from the average of the CAU where they live, it has been shown that community data is an adequate proxy for personal data.¹⁰

Denominator population data were provided from the Census by Statistics New Zealand; analysis of the 2006 Census had not been completed when the study was undertaken and projections from the 2001 Census were used.

The number of discharges and weighted discharges was calculated by department for each year. The population rate was expressed as an intervention ratio (IR) which allows adjustment for both population growth and aging. Using 2005/06 rates for each of 10 age groups, the number of discharges, which would have occurred had those rates applied, was calculated for each year back to 1991/02. The IR is modelled as the actual number divided by the expected number.

The IR was also used to describe the deviation of each district from the national average. Here, to allow for differences between the populations of each district, socioeconomic status (SES) (NZDep 1, 2 & 3; 4, 5, 6 & 7; and 8, 9, & 10) and ethnicity (Maori, Pacific, and Other) were included in the model. Thus, the expected number of discharges by district was calculated using the sum for each of $90 (10 \times 3 \times 3)$ age, SES, and ethnicity groups.

A significant amount of deviation from the norm can occur by chance, especially if an event is rare. A 95% confidence interval was calculated for the IR, using the formula:

 $\exp(IR \pm 1.96 \times sqrt[1/obs])$

where obs is the observed discharge count.

This is the accepted confidence formula for standardised incidence ratios of the form Observed/Expected. The formula is derived from the assumption that the natural logarithm of the IR is normally distributed, and the mean and variance of the weighted discharge counts match those of a Poisson distribution.

The rate of discharge for a district service was considered to be discrepant when the lower (95%) confidence limit of the IR above was above 1.1 or the higher confidence limit was below 0.9. These values were chosen on the basis that a difference of more than 20% in admission rate would have meaning at a clinical level.

To measure the overall degree of variation, a Coefficient of Variation (CoVar) was calculated as the mean absolute variation of the IRs of all districts from the national norm. Thus a value of 0.10 indicates that, on average, the district IRs are 10% away from (above or below) the national mean.

In calculating CoVar weighted discharges were used to recognise, in calculating the total volume of care, the fact that some discharges represent "more healthcare" than others. The mean was weighted by population size to recognise that variation in small districts is less important, nationally, than variation in larger ones.

The level of variation between districts was first calculated for discharges occurring in the 3 years from 2002 to 2005. It has been shown that estimates of variation decrease if more than 1 year is considered and this, along with using weighted discharges and a weighted average for CoVar, produces a more conservative estimate of variation. CoVar was also calculated for each year from 1991 to 2006.

Results

Changes over time—Table 1 shows the number of cases and weighted cases, by department, recorded in 1991/92 and 2005/06, with the percentage change and the percentage change adjusted for the increase in population number and age. For all discharges, there has been an increase of 58.8% but the average weight of a case has

decreased by 5.2% so that the increase in weighted cases is 50.5%. When the increase is adjusted for population growth and aging, the increase, over 15 years, is 17.9%.

Table 1. Cases and weighted cases 1991/92 and 2005/06; percentage (%) change in cases and weighted cases, with & without adjustment for population number & age

Cases	1991/92	2005/06	% change	% change volume adjusted*
Medical cases	164477	309913	88.4	48.4
Medical weighted	156973	230638	46.9	16.2
Mean weight	0.95	0.74	-22.0	
Surgical cases	152220	209336	37.5	9.8
Surgical weighted	182000	283937	56.0	12.1
Mean weight	1.20	1.36	13.4	
High cost cases	26384	47546	80.2	47.0
High cost weighted	33234	64784	94.9	51.3
Mean weight	1.26	1.36	8.2	
Maternity cases	106269	135659	27.7	22.6
Maternity weighted	80340	85571	6.5	8.1
Mean weight	0.76	0.63	-16.6	
TOTAL cases	457731	727096	58.8	31.2
TOTAL weighted	459945	692387	50.5	17.8
Mean weight	1.00	0.95	-5.2	

^{*}Adjusted for population.

The pattern differs by department. Medical cases have increased the most (88.4%) but the average weight has decreased (-22%) so the increase in weighted discharges is 46.9% and the increase adjusted for population factors is 16.2%. Surgical cases have increased 37.5% but the average weight has increased (13%) so the increase in weighted discharges is 56% and the increase adjusted for population factors is 12.1%.

High-cost cases have increased 80.2% and the average weight has increased (8%) so the increase in weighted discharges is 94.9% and the increase adjusted for population factors is 50.3%. Maternity cases have increased 27.7% and the average weight has decreased (-17%) so the increase in weighted discharges is 6.5% and the increase in population adjusted cases is 8.1% (reflecting a decrease in the relevant age group).

Figure 1 shows the percentage change in weighted discharges adjusted for population size and age between 1991/92 and 2005/06. Medical discharge rates increased between 1997 and 2000 and surgical discharge rates increased between 1997 and 1998; they were relatively stable before and after that period. High-cost discharges have increased progressively since 1994. Maternity discharges have changed little overall but manifest several abrupt year-to-year changes. Had the change in this department been measured from 1992 to 2004, instead of from 1991 to 2005, a reduction of 17%, instead of an 8% gain, would have been recorded.

1.60 1.50 1.40 - Medical Surgical 1.30 Hi Cost Maternity 1.20 Total 1.10 1.00 0.90 96 97 95 98 99 Year Beginning

Figure 1. Percentage change in population- and age-adjusted weighted discharges 1991/92 and 2005/06*

*The 2005/06 values were used as the norm in calculating the intervention ratio but the graph has been modified so that the each department starts (rather than ends) at zero.

Variation between districts—The coefficient of variation across districts by department for the 3 years 2002/05 was 0.07 for medicine, 0.06 for surgery, 0.08 for high-cost, and 0.035 for maternity. Table 2 lists those districts that meet the criteria for discrepancy.

For medicine, IRs range from 0.81 to 1.16; there are four districts with levels of medical discharge that are significantly below, and two which are significantly above, the national mean.

For surgery, IRs range from 0.88 to 1.20; there is one district with a level of surgical discharge that is significantly below, and four districts with levels of surgical discharges that are significantly above, the national mean.

For high-cost discharges, the range of IRs is 0.80 to 1.24 and there are three districts with levels of high-cost discharges that are below, and one which is above, the national mean.

For maternity the range of IRs is 0.85 to 1.08 and there is one district with a level of maternity discharges that is significantly less than the national mean. In total there are 13 departments out of 84 (15%) which appear to be discrepant.

Table 2. Range of intervention ratios, district departments with unexpectedly high or low values, and the confidence interval of the estimate of the IR (2002–2005)

District departments	High Intervention ratio	Low 95% CI	High 95% CI	Low Intervention ratio
Medical				
MidCentral		0.80	0.83	0.81
Capital & Coast		0.84	0.86	0.84
Nelson Marlborough		0.83	0.87	0.85
Otago		0.87	0.90	0.88
Lakes	1.10	1.10	1.13	
Wairarapa	1.16	1.13	1.20	
Surgery				
MidCentral		0.87	0.90	0.88
South Canterbury	1.13	1.11	1.16	
Whanganui	1.14	1.13	1.17	
Otago	1.18	1.17	1.20	
West Coast	1.20	1.18	1.25	
High-cost				
Otago		0.78	0.84	0.80
Nelson Marlborough		0.81	0.87	0.83
Capital & Coast		0.83	0.88	0.85
Hawke's Bay	1.24	1.22	1.29	
Maternity				
Nelson Marlborough		0.83	0.89	0.85

It is possible that variation only reflects differential usage of departments; thus, there might be compensation for low surgical volumes in high medical ones. Table 3 shows the relevant correlation coefficients. It will be noted that surgery is positively correlated with medicine (r=0.21) which suggests that there is little overall trade-off between the two. In passing, it may be noted that rates of surgery are negatively correlated (r=-0.49) with district population size while maternity is positively (r=0.28) so correlated.

Table 3. Correlations between population-adjusted intervention ratios for departments (and district populations)

Department	District population	Medicine	Surgery	Maternity	High-cost
Medicine	-0.16	1			
Surgery	-0.49	0.21	1		
Maternity	0.28	0.35	-0.26	1	
High-cost	-0.05	0.43	-0.25	0.55	1

Figure 2 presents the coefficient of variation across districts by department for each year 1991/92 and 2005/06. There is a modest decrease in variation for medicine (0.13 to 0.12) which mainly occurred between 1993 and 1995. There is also a modest decrease in variation for surgery (0.10 to 0.09) which mainly occurred between 1997 and 1999. There is a greater decrease in variation for high-cost discharges (0.17 to 0.12) and maternity (0.14 to 0.06), sustained over the period 1991 to 2000.

The year-to-year level of variation for each department has been erratic with movement against the downward trend. These values, based on single years, are higher than those quoted above for a 3-year period.

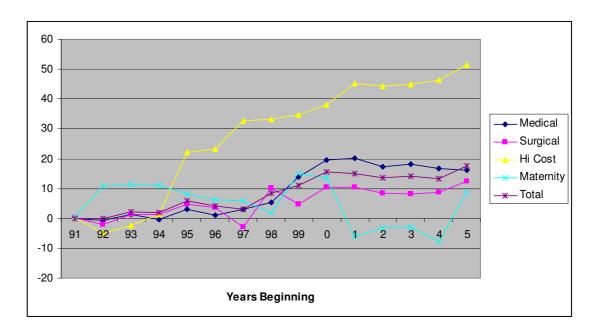


Figure 2. Weighted coefficient of variation by department 1991/92 and 2005/06

Discussion

Confidence in the analysis above depends on the accuracy of the data. Hospitals have had an incentive to code to DRGs with higher weights. The fact that the number of discharges, as well as the weighted discharges, have increased, and the reduction in mean weight for medicine and maternity, suggest that growth in service levels are real. This conclusion is supported by the lack of abrupt changes in rates noted for medicine and surgery.

The changes in rates of maternity services, particularly the elevation between 1998 and 2000, suggest differences in coding practices.

There is anecdotal evidence that visits to the Emergency Department lasting more than three hours might or might not be reported as admissions. Similarly, in one district, public urology is undertaken by a private contractor and some cases are not entered into the NMDS. This might increase or decrease the degree of variation.

The assessment of variation may be affected by the fact that age, SES, and ethnicity are only partial proxies for need; other variables not included in the model include district variation in:

- Rates of road traffic accidents
- Use of private surgical facilities
- Access to particular services (e.g. termination of pregnancy)

- Age incidence of a particular need (e.g. later urban child bearing)
- Improved access to primary care
- Adoption of out-patient management of some illnesses

Local factors, that could increase or decrease need for each type of hospital care, should be examined before concluding that any discrepancy in rates is undesirable. High rates (indicating that everyone with a particular need is being treated) or low rates (indicating effective prevention) could become appropriate goals in different circumstances.

There is no doubt that hospital throughput has increased markedly over the study period with discharges increasing by 58.8% and weighted discharges by 50.5%. When the part of the increase related to population growth and aging is removed, an increase of 17.8% remains. This represents an increase in the relative intensity of public hospital services provided to the New Zealand public; it was most marked under the HFA.

High-cost discharges have increased more rapidly than those from other departments; such discharges made up 7% of all (weighted) discharges in 1991/92 and 9% of them in 2005/06. Maternity discharges remained relatively stable—as would be expected.

The recent investment in elective surgery can be expected to contribute to further growth in surgery; it will be interesting to see if it leads to a reduction in the degree of variation.

There is an apparently significant variation in rates of admission across districts after accounting for population differences. As predicted, maternity discharges vary least and the residual CoVar of 0.035 can be attributed to factors outside the model.

If maternity and high-cost discharges are excluded, 11 of 42 departments (26%) appear to be significantly above or below the national mean over a 3-year time period. Other work has shown that this variation conceals a greater degree of variation for individual specialties and for types of admission within each specialty. The estimate of variation across the study period shows only a modest decline; for medicine this occurred under the RHA, for surgery under the HFA.

Future analysis will consider individual specialties and components of specialties, and examine the effect of private surgery on variation. This analysis does not directly address the adequacy of hospital services which should be studied through examination of the needs of those on the margin between community and hospital care; such a study, *Pathways to Surgical Care*, has been completed and will be submitted for publication in the near future.

Conclusions

The level of hospital admissions in New Zealand has increased dramatically since 1991 and represents real growth in the intensity of service after allowing for population growth and aging. The rate of real growth has been approximately 1% per annum.

Reduction in variability has been only modest. If future investment in hospital care is to have maximal positive impact, reduction of variability which is not related to differences in need should be a priority.

Competing interests: None known.

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Acknowledgements: The author acknowledges the contributions of Patrick Graham (Statistician) and Dean Papa (Data Analyst).

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THE NEW ZEALAND MEDICAL JOURNAL



Journal of the New Zealand Medical Association

Mapping progress: the evaluation and monitoring work of the Cancer Control Council of New Zealand 2005–2007

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Abstract

The Cancer Control Council of New Zealand was established in 2005 to provide an independent, sustainable focus for cancer control. One of its key roles is to monitor and review implementation of the Cancer Control Strategy.

In early 2007, the Evaluation and Monitoring Working Group of the Council undertook a monitoring exercise on all Phase 1-designated milestones in the Cancer Control Strategy Action Plan 2005–2010. Phase 1 designates those actions to be undertaken in the first 1 to 2 years of the Action Plan i.e. 2005–2006. In addition, the Council commissioned an evaluation of the developing regional cancer networks.

The evaluation and monitoring report *Mapping Progress: The First Two Years of the Cancer Control Strategy 2005-2010* was launched in August 2007 and found that 71% of all Phase 1 milestones were either achieved or in progress. The Council noted that Goals 1 and 2 (of the Strategy) were proceeding most rapidly and thoroughly. However, while there were good achievements in certain areas of Goals 3, 4, 5, and 6, overall progress was less systematic. Phase 1 milestones that aim to address cancerrelated inequalities were also assessed and found to have marginally better progress than the overall milestones, but did not reflect a systematic approach to addressing inequalities.

The Council is now undertaking a consultation phase to seek feedback on the evaluation and monitoring report and input into further monitoring activities.

Background

From 1999, a series of articles appeared in the *New Zealand Medical Journal* discussing the need for a concerted approach to cancer control in New Zealand.^{1–5} In 2000, cancer control was prioritised in the *New Zealand Health Strategy*⁶ where one of the 13 identified population health objectives was "to reduce the incidence and impact of cancer". This was followed by the publication of the *Cancer Control Strategy* (the Strategy) in 2003⁷ and the *Cancer Control Strategy Action Plan* in 2005.⁸

The Cancer Control Council of New Zealand is an independent council appointed by and reporting directly to the Minister of Health. The Council was established in 2005 under section 11 of the New Zealand Public Health and Disability Act 2000 to provide an independent, sustainable focus for cancer control.

The Council's five key roles are to:

- 1. Monitor and review implementation of the Strategy.
- 2. Provide independent strategic advice to the Minister of Health, the Director-General of Health, district health boards, and non-government organisations on matters related to cancer control.
- 3. Foster collaboration and cooperation between bodies involved in cancer control.
- 4. Foster and support best practice in, and an evidence-based approach to, improvements in the effectiveness of cancer control.
- 5. Establish and maintain linkages with overseas cancer control agencies.

The purpose of this paper is to briefly describe the Council's evaluation and monitoring of the first 2 years of the Action Plan. A full report has been published elsewhere, and provides more detail for the interested reader.

Evaluation and monitoring

Monitoring is needed to ensure the Strategy is achieving its dual aims of reducing the incidence and impact of cancer and reducing inequalities with respect to cancer. Ongoing monitoring and periodic review were identified as integral components of both the Strategy and the Action Plan and would "provide government and nongovernment stakeholders with clear and credible accountabilities against which the actual performance of the Action Plan and Strategy can be measured and reported". ⁷

Regular monitoring will indicate whether the specific actions in the Action Plan are meeting their expected outcomes and the milestones for each action are being achieved. In addition, monitoring and new research can identify areas that can be improved.

The Council undertakes monitoring, evaluation and review at three different levels of the *Cancer Control Strategy*, and has developed an evaluation and monitoring framework to inform the Council's approach to these activities. The framework was developed in line with international research into monitoring of cancer control programmes¹⁰ and emphasises the principles of:

- Being independent of providers and funders of services as far as possible.
- Using available data sources wherever possible, to maximise efficiency, to reduce duplication and to control compliance burden.
- Providing timely measurement of progress and outcomes of the implementation of the Cancer Control Strategy.

The full evaluation and monitoring framework is available on the Council's website: www.cancercontrolcouncil.govt.nz.

There have been two major foci of the Council's evaluation and monitoring work thus far:

- A high-level monitoring of Phase 1 activities and milestones as identified in the Action Plan⁸
- A more in-depth evaluation project of the establishment of regional cancer networks.

These two foci are summarised below.

Monitoring of Phase 1 activities

The Action Plan, covering the 5 years from 2005–2010, identifies priority actions to be undertaken in the first 1 to 2 years (Phase 1) and longer-term actions which will generally occur within 3 to 5 years (Phase 2). These actions are listed under the six goals of the strategy. Under the actions are specific milestones for monitoring—of which 152 milestones were listed as Phase 1 priorities.

Methodology—The Evaluation and Monitoring Working Group of the Council undertook to provide a monitoring report on all Phase 1-designated milestones in the Action Plan. March 2007 was the nominal end of Phase 1—i.e. the first two years of the Action Plan. However, the Working Group recognised that actions described in the Action Plan may have had a long lead-in time and may therefore not have had a full 2 years to be fully achieved. The Working Group took this into account when assessing progress.

For this first evaluation and monitoring report, a decision was made to provide comment on every Phase 1 milestone in the Action Plan, in a 'tick the box' manner.

Due to time constraints it was not considered possible to approach every stakeholder organisation listed in the Action Plan. A subset of key stakeholders was chosen by examining each Action Plan outcome, based on one or more of the following criteria:

- Stakeholder is involved in cancer control activities for this outcome.
- Stakeholder has a direct interest in this outcome.
- Stakeholder is well-defined and contactable.

A final contact list of 56 stakeholders was produced, which included Ministry of Health directorates, government ministries/agencies, district health boards, the University of Otago, cancer charities, professional bodies, special interest committees, and other non-governmental agencies.

Stakeholders were approached through communication to their chief executive officers, with a request to provide information on their organisation's contribution to progress against the Action Plan. Reporting templates were specifically tailored to each organisation, depending on their areas of responsibility or interest, as listed in the Action Plan. Stakeholders were also invited to provide comments on their perceptions of progress in implementing the Strategy.

A month was allowed for responses. This timeframe was chosen in line with similar requests from other monitoring agencies. However, the Council acknowledges that timing this request towards the end of the financial year, without a longer notification

period, may have added to an already busy and stressful time. The Council will consider moving its reporting timeframe to a less busy time of year for further iterations of this monitoring report.

Non-responding stakeholders were followed up with a further email, telephone calls, and finally a letter to the chief executive officer, noting the Council's official role in monitoring of the Action Plan and requesting that information be made available.

Analysis—For analysis and assessment of progress, the Working Group relied on responses from stakeholders and published information made available to it.

Care was taken to specifically assess the 152 milestones designated as Phase 1, not the overlying actions or objectives.

Four levels of assessment were assigned:

- "Achieved"—a defined milestone was completed.
- "In progress"—a very wide-ranging category, ranging from projects nearing completion through to projects recently initiated and longer-term projects that may not have a clear end date.
- "Delayed"—no activity specific to the milestone.
- "Insufficient information available"—either no information was received, or the information was insufficient to determine progress.

For ease of reading and to maintain the familiarity which stakeholders have developed over the first 2 years of the Action Plan, a format was chosen for the evaluation and monitoring report which echoed the layout of the printed Action Plan. For each of the six goals of the Strategy, overall progress was assessed, stakeholder comments were collated and the Council provided an overview of commendations, recommendations, and comments.

Issues arising from the Action Plan—During the analysis and assessment stages of producing the evaluation and monitoring report, it became apparent that there are aspects of the Action Plan which are not well adapted to the need for monitoring of progress. These included poor definition of some stakeholder groups, no lead stakeholder identified as responsible for implementation of each action, milestones not always sufficiently defined or inconsistent and areas where stakeholder or milestone information was missing. These issues will be addressed by the Council, in consultation with the cancer control community, as they look towards the implementation of Phase 2 of the current Action Plan and the production of the next Action Plan (2010-2015).

Results

The evaluation and monitoring report *Mapping progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010* was launched on 23 August 2007.

The Action Plan lists 101 named stakeholder groups or organisations as "key stakeholders". In addition, less defined groups such as "PHOs", "Maori health providers", "research funders", "employer organisations", and "consumer groups" are also listed as "key stakeholders".

The Council decided to draw up its list of stakeholders to approach for information from the 101 named stakeholders, using the criteria listed in the Methodology section above. Table 1 shows the response rates of the chosen key stakeholders. Overall, the response rate was 85.6% of the chosen total of 56, or 48/101 = 47.5% of all named stakeholders in the Action Plan.

Table 1. Response rates of different groups of key stakeholders to request for monitoring information

	Information request from Council	Initial response provided by stakeholder	Outcome/ milestone information provided by stakeholder	Did not respond or provide data for information request
Directorates at the Ministry of	4	4	4	0
Health				
District health boards	21	21	19	2
University	1	1	1	0
Government ministries/agencies	7	6	5	2
Non-government organisations	14	14	11	3
Professional bodies	6	6	5	1
Committees	3	3	3	0
TOTAL	56	55 (98.2%)	48 (85.7%)	8 (14.3%)

Table 2 details the implementation status of all 152 Phase 1-designated milestones, as determined by the Council:

Table 2. Implementation status of Phase 1-designated milestones by goal

	MONITORING AGAINST ALL MILESTONES					
	Achieved	In progress	Delayed	Insufficient information available for monitoring	Goal total	
Goal 1	9	29	4	3	45	
Primary prevention of cancer						
Goal 2	4	3	3	-	10	
Effective screening and early detection						
Goal 3	4	18	5	4	31	
Effective diagnosis and treatment						
Goal 4	4	14	10	_	28	
Improve the quality of life for those with						
cancer						
Goal 5	1	15	11	2	29	
Improve the delivery of cancer control						
services						
Goal 6	1	6	_	2	9	
Cancer control research and						
surveillance						
TOTAL	23 (15%)	85 (56%)	33 (22%)	11 (7%)	152	

Overall, 15% of Phase 1 milestones have been achieved, supported by a further 56% of Phase 1 milestones in progress; 22% of Phase 1 milestones were assessed as delayed, while insufficient information was available to assess the remaining 7%. For more specific detail on the progress of Phase 1 actions, the full report is available at www.cancercontrolcouncil.govt.nz

The Council also identified specific actions and milestones in Phase 1 that aim to address cancer-specific inequalities, such as ethnicity, socioeconomic status, and rurality. Overall, 15% of these inequality-related milestones have been achieved and a further 64% are in progress. 9% milestones were delayed, and the Council was unable to assess the remaining 13% due to insufficient information. While progress appears satisfactory, much of this progress relates to specific activities at a district or regional level rather than a systematic approach to addressing inequalities.

Evaluation of the development of the regional cancer networks—The establishment of regional cancer networks was the very first of the Phase 1 overall priorities, as identified in the Action Plan. The establishment of these networks is still at an early stage. In 2007 the Council commissioned a formative evaluation of the implementation stage of the four regional cancer networks. A summary report is included in the *Mapping Progress* report.

The formative evaluation found that the four networks are in the early stages of development, with each having started at considerably different points and each having a different structure. Each network has understood the need to actively involve consumers and NGOs, but has interpreted this requirement in different ways. The review also suggested a lack of clarity within the New Zealand cancer control community regarding the respective roles of the Council and the Ministry of Health.

The evaluation report contains sixteen recommendations for the Council, the Ministry of Health and the regional cancer networks. The Council is currently assessing and prioritising these recommendations for implementation.

Discussion

Strengths/limitations of methodology—By selecting a subset of the stakeholders listed in the Action Plan, the Council was able to ensure that this subset represented the entire range of stakeholders and identified key implementers of specified outcomes. Practically, it also ensured that a sufficiently wide range of responses was obtained, without generating so much information that it could not be analysed within the required timeframe. However, this may have meant that smaller, but still important, stakeholders were not consulted. The Council has noted all responses to the *Mapping Progress* report and will ensure that interested stakeholders are included in future monitoring and evaluation consultation.

This methodology uses a "tick-the-box" approach, targetting each specified milestone designated for completion in Phase 1. This approach has given a very clear point-in-time picture of the state of implementation of the Action Plan. However, by virtue of this approach, it may have sometimes not captured the complexity and interaction of certain programmes or actions. The Council is considering its approach to future monitoring and evaluation activities.

Overall progress in Action Plan goal areas—Goal 1 (primary prevention of cancer) and Goal 2 (screening and early detection of cancer) have shown the most rapid and thorough progress, drawing on the long-standing programmes of tobacco control and the National Screening Unit and the intensive efforts to develop strategies on Healthy Eating Healthy Action in the past 2 years (see Table 2).

Within Goals 3–6 (effective diagnosis and treatment, support, rehabilitation and palliative care, improved delivery of services and research and surveillance), there have been good achievements, notably in adolescent oncology, the Late Effects Assessment Programme, the establishment of the New Zealand Cancer Treatment Working Party, investigatory projects into cancer patient journeys, a stocktake of cancer information resources, a cancer workforce stocktake and a research funders forum. However, overall progress in these goals has been uneven, with a disproportionate number of milestones delayed compared to milestones achieved (see Table 2).

Activities within Goals 3, 4, and 5 will be advanced through the establishment of the regional cancer networks and the recent establishment of a supportive care expert advisory group. Goal 5, which cuts across all other goals of the Strategy, includes major issues of the health workforce, initiatives with Maori and consumer representation, which are now underway. Under Goal 6, the Council is now deciding how to draft a strategic approach to cancer research in New Zealand.

The Council also states that improving the New Zealand Cancer Registry and developing a National Cancer Management Dataview are both critical to the long-term success of the Strategy.

Delays of concern to the Council—Within the 33 milestones (22% of the total of Phase 1 milestones) which were assessed as delayed, the Council noted particular concern at the lack of progress in the following areas:

- Goal 2—delays in assessing the extent to which early detection and diagnosis
 are contributing to New Zealand's high cancer mortality rates and identifying
 interventions that could reduce inequalities in cancer mortality and morbidity.
- Goal 3—a delay in the establishment of a Supportive Care Expert Advisory Group (as per outcome 62), which has led to delays in consecutive outcomes and milestones. This group has now been established (July 2007) and will need to address plans for the achievement of Phase 1 milestones.
- Goal 4—delays in the establishment of a national leadership body for palliative care, which has contributed to difficulties in assessing and standardising palliative care provision across all DHB areas. The Council notes that progress has recently been made (July 2007) towards the establishment of such a leadership body and looks forward to its contribution towards achieving milestones within palliative care.
- Goal 5—delays in developing a coordinated national cancer workforce strategy. The Council was pleased to receive a copy of the Ministry of Health's report Cancer Control Workforce: Stocktake and Needs Assessment, but comments that this report may have underrepresented some of the gaps in workforce across the spectrum of cancer control. The Council will work

towards identifying lead implementer stakeholders for areas of delay within this goal.

Recommendations for ongoing work on Phase 1 milestones—Phase 1 activities will be continuing over the next year, particularly for the 23 Phase 1 milestones also designated for action in Phase 2 (2007–2010). Areas of action which may benefit from more concerted emphasis include the delays identified above and the overall priority areas for Phase 1 implementation which were included in the Action Plan. As yet, no complementary list of prioritised actions for Phase 2 has been developed, but the Council has consulted with the cancer control community and is considering collating a list of suggested priority areas.

Conclusion

The Council recognises that the processes it undertook in obtaining information for this first evaluation and monitoring report may not have been optimal, may have lead to additional workload on some stakeholders and may have not enabled all relevant information to be obtained. The Council welcomes feedback on all aspects of its work programme and of the evaluation and monitoring report.

Since the launch of the report, the Council has begun a process of formal consultation with the cancer control community to assess progress to date, plan further monitoring processes and seek input into longer-term projects such as the upcoming review of the Action Plan. The Council will also undertake further work to investigate the progress made on the outcomes and actions relating to cancer-related inequalities.

Competing interests: None known.

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Acknowledgements: The members of the Council's Evaluation and Monitoring Working Group are Professor Tony Blakely, Professor John Gavin, Dr Beverley Lawton, Ms Helen Glasgow, Dr Garry Forgeson, and Dr John Childs

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THE NEW ZEALAND MEDICAL JOURNAL



Journal of the New Zealand Medical Association

From screening criteria to colorectal cancer screening: what can New Zealand learn from other countries?

Caroline Shaw, Ruth Cunningham, Diana Sarfati

Abstract

New Zealand is currently exploring how population-based colorectal cancer (CRC) screening will be implemented. The United Kingdom (UK), Australia, France, Italy, Spain, Finland, Denmark, the Netherlands, and Switzerland have conducted or are currently conducting pilot/feasibility studies. The UK, Australia, Finland, Canada, France and Italy are all in the early stages of implementing population-based CRC screening programmes. Most of these countries have lower CRC mortality rates than New Zealand. New Zealand is in a good position to learn from this overseas experience. Some of the key areas that will require careful consideration include; the best use of a population register to identify and invite eligible participants; the type of screening test to be used; ensuring adequate colonoscopy capacity; efficient and effective information systems; the management of high-risk groups; and how to ensure that all population groups benefit from screening.

New Zealand has some of the highest rates of colorectal cancer (CRC) incidence and mortality in the world. In the absence of effective primary prevention strategies, efforts have concentrated on screening and improving treatment in order to decrease mortality from CRC. At least four randomised controlled trials (RCT) of CRC screening (using the guaiac faecal occult blood test Haemoccult) have been undertaken. Meta-analysis of the RCT conducted in Nottingham, Minnesota, Funen, and Goteborg show a 16% reduction in population CRC mortality can potentially be achieved by screening.

New Zealand has twice considered whether a national population based screening programme would be appropriate. The most recent review concluded that CRC screening largely met the National Health Committee screening criteria for population based screening programmes. However there were still unanswered questions, mainly relating to the type of faecal occult blood test (FOBT) to be used and the ability of the healthcare system to deliver diagnostic services (i.e. colonoscopy after a positive screening FOBT).

The advisory group considering this issue recommended that a feasibility study, involving at least a prevalence round of screening in a community setting, be conducted to examine these, and other, aspects of screening. The advisory group specifically noted that a feasibility study should be conducted prior to a final decision on a national programme. Assuming a feasibility study was deemed successful it would be followed by a pilot programme, then a full programme roll-out. This advice was endorsed by other groups providing advice to the Ministry and Minister of Health. Recently the Minister of Health announced that New Zealand will proceed with CRC screening, although specific details are yet to be announced.

Establishing effective screening programmes is always demanding, but colorectal cancer screening has some particular challenges:

- The mortality reduction potentially achievable from CRC screening is modest at best; meta-analysis of the RCTs of screening shows a 16% mortality reduction, compared to 20% for breast cancer screening.^{3,9}
- Participation in CRC screening appears to be lower than other screening programmes; most pilot studies have shown only moderate participation.
- Selection of the type of screening test is problematic. There are two types of faecal occult blood tests; guaiac (FOBTg) and immunochemical (FOBTi). They use different methods to detect blood in faeces and neither test is ideal. FOBTg is the screening test for which there is RCT evidence, but it only has a sensitivity of about 55%, meaning that almost half of people with cancer will have a negative screening test. FOBTi are more sensitive for detecting blood or blood products in faeces, processing can be automated and they are 'set' allowing some alteration of what constitutes positive. Using FOBTi would mean more cancers are detected, but also that considerably more colonoscopies would be required. There is some research evidence suggesting higher participation compared with FOBTg, 19,20 but there is currently no RCT evidence supporting the use of FOBTi in population screening.
- Complications of the required follow up diagnostic test, colonoscopy, while rare, are potentially serious (e.g. perforation of the bowel).

While other screening tests—such as flexible sigmoidoscopy, CT colonography, and faecal DNA—are being explored, as yet evidence for these options is limited. ^{21–23}

This paper aims to review the feasibility and pilot studies that have been completed overseas, in order to inform planning for CRC screening in New Zealand.

International situation

Internationally, there seems to be a (slow) transition occurring in CRC screening policies. While opportunistic testing remains the most common practice in OECD countries, there is an increasing move towards adoption of population based FOBT screening, and ongoing research interest in flexible sigmoidoscopy. ^{24–26}

The United Kingdom (UK), Australia, France, Italy, Spain, and Finland have all conducted feasibility or pilot studies. ^{10–17,27–30} Denmark, the Netherlands, and Switzerland are currently conducting pilot or feasibility studies, although no details of design or results have yet been published. ^{25,26,31,32}

The UK, Australia, Finland, Canada, France, and Italy are all in the early stages of implementing population-based CRC screening programmes run at either a state or national level. ^{10,12,25,33–38} Canada does not appear to have conducted a population-based pilot or feasibility study prior to commencing implementation of a screening programme.

All of these countries, with the exception of Denmark, have lower rates of CRC mortality than New Zealand.¹

What are the key findings from international CRC screening pilot/feasibility studies?

Conducting and evaluating a pilot or feasibility study results in a wealth of information. Table 1 summarises some of the key aspects of the design and results of pilot studies conducted in the UK, Australia, France, Spain, and Italy, and the first phase of the implementation of the Finnish screening programme which was explicitly designed to assess the feasibility of screening. 12,28

The terms feasibility study and pilot study are largely synonymous in the literature. The design of these studies is also identical, involving (at least) a prevalence round of screening in a community setting. The intent of studies also seems similar; to test the viability of screening in the community and to inform planning for any national programme.

Design of the screening pathway—Screening for colorectal cancer involves a pathway of activities, from inviting people to be screened through to ensuring they receive best practice treatment if they are diagnosed with the condition. The details of this specific pathway must be determined before screening can be commenced. Despite different health systems, there are a number of commonalities in the details of screening pathway design of the pilot studies discussed in Table 1.

All studies had biennial screening and used a population register to identify and invite people to participate in screening. Colonoscopy was the diagnostic investigation in all pilot studies, although second-line investigation protocol (e.g. double contrast barium enema) varied slightly. Most countries had exclusion criteria for those at high risk of colorectal cancer (as they are not suitable for population screening), although these varied slightly. ^{10–17,28}

Some of the differences between pilots included:

- *Age ranges*—these varied slightly, although all were within 50–74 years. No rationale for particular age range selected was stated.
- Type of screening test—Spain, France, Finland, and the UK used guaiac faecal occult blood tests (FOBTg) in their pilot studies. Australia and Italy used immunochemical faecal occult blood tests (FOBTi).
- Definition of a positive FOBTg test—France and Finland regarded any positive result for blood on any of the six samples as requiring colonoscopy follow up. Spain and the UK had a 'weakly positive' category that required repeat testing.
- The involvement of primary care in the screening pathway—General practitioner referral for colonoscopy was required after a positive result in the Australian, French, and Finnish programmes. The other countries had a more centralised screening programme, with colonoscopy referral occurring directly from the programme. ^{10–17,28}

Table 1. Results of international pilot studies of CRC screening

Country name	Australia	UK	Italy (Florence)	France	Spain	Finland
Age of eligible population	55–74	50–70	50–70	50–74	50–69	60–69
Population invited to be screened	60,792 (56,907 actually eligible)	478,250	15,235	182,981 (163,707 actually eligible)	64,886 (63,880 actually eligible)	52,994 (52,994 actually eligible)
Number (%) participated in screening	25,840 (45.4% of eligible)	276,819 (57.9% of invited)	6,418 (42.1% of invited)	90,706 (test completion) (55.4% of eligible)	10,987 (17.2% of eligible)	37,514 (70.8% of eligible)
Number (%) of positive tests	2308 (9%)	5050 (1.9%)	268 (4.2%)	3100 (3.4%)	372 (3.4%)	803 (2.1%)
Time to follow up colonoscopy	9 days (mean) from FOBT result to GP consultation: 38.5 days (mean) from GP consultation to colonoscopy	2-6 weeks average	Not stated	Not stated	41 days (median time from positive FOBT to colonoscopy)	82% had colonoscopy within 3 months of test, 91% within 4 months.
Attended colonoscopy after positive FOBT	1,265 (55%)*	4,116 (81.5%)	231 (86.2%)	2,724 (87.9%)	334 (89.8%)	723 (90.0%)
Colonoscopy complications	Not stated	2 perforations (0.05%) 23 admissions	Not stated	2 perforations, 4 bleeding (0.2%) 9 admissions	1 perforation , 3 bleeding	Not stated
Number of cancers detected (% of people screened)	67 (0.26%) (only 20 are confirmed by pathology)	552 (0.19%)	33 (0.51%)	206 (0.23%)	23 (0.21%)	62 (0.16%)

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1279/3186/

Country name	Australia	UK	Italy (Florence)	France	Spain	Finland
Number of adenomas detected (% of people participated in screening)	176 advanced (0.68%) (these do not appear to be confirmed by pathology)	1,388 (0.5%)	75 (1.16%)	958 (1.06%)	109 (0.99%) (high risk 79)	312 (0.83%)
Positive predictive value (denominator number of colonoscopies)	Cancer: 5.2% High risk adenoma 13.9% (note these were not pathologically confirmed cancers and adenomas)	Cancer: 10.9% Adenoma: 35.0%	Cancer: 14.3% Adenoma: 32.5%	Cancer: 7.6% High risk adenoma: 23.6%	Cancer: 6.2% High risk adenoma: 21.2%	Cancer: 8.6% Adenoma: 43.2%
Stage of cancers detected	Not known	Dukes stage A: 48%** B: 25% C: 26% D: 1%	Astler and Coller A: 39.3% B1: 33.3% B2: 12.1%	TNM stage I: 47.6% II: 23.8% III: 20.5% IV: 8.1%	TNM stage (for cancers from 2 rounds of screening) I: 41.7% II: 19.4% III: 27.8% IV: 11.1%	Not stated

^{*}Likely to be an underestimation due to data collection issues, however many of those with positive FOBT did not attend their GPs, which was required for colonoscopy referral.

All information for this table is sourced from 10-17, 28

^{**} Including polyp cancers.

Participation in CRC screening programmes—Participation is a key factor in screening programme success. As detailed in Table 1, participation varied considerably in the different studies, from 17% in Spain to 70% in Finland. The remainder of studies had participation between 42–58%. 10,13–17

The two countries that used FOBTi did not have higher participation compared to countries using FOBTg, which is somewhat inconsistent with research evidence. 19,20

Ongoing participation in screening programmes is crucial, particularly in a programme with low screening test sensitivity. Current information on ongoing participation is limited as only Spain and England have reported on second (incidence) rounds of screening. In Spain, participation increased from 17% to 22%, but in England it decreased from 58.5 to 51.9%. This latter result is of particular concern.

Screening test issues—The screening test positivity rate varied considerably in the first round of screening in the studies summarised (Table 1). This is due to a number of factors, including the different test types used (FOBTg vs FOBTi), different measures of test positivity, and different underlying disease incidence. For example, in the UK using FOBTg there was a positivity rate of 1.9% while in Australia, which used FOBTi, the rate was 9%. ^{14,15}

Establishing an appropriate threshold for a positive test in immunochemical FOBT appeared to be a challenge in Australia where two different FOBTi were tested in the pilot study. Initially 13.7% of people were test positive on one of the immunochemical tests being trialled, however after a change in the "test kit or the test analysis" this declined to 7.1%. Different positivity levels have implications for the sensitivity and specificity of the screening test, as well as for the numbers of diagnostic colonoscopies required.

Colonoscopy—Colonoscopy rates (the proportion of people attending for colonoscopy following a positive screening test) were over 80% in all but the Australian study (which was 55%) although data issues mean that the Australian rate is likely to be an underestimate. Over 85% of all colonoscopies were completed adequately. Few serious complications were described in those studies which reported complication rates. Perforation rates varied between 0.05% and 0.2%. 10–17,28

Colonoscopy capacity was a concern in many of the pilots. The UK, which had the lowest test positivity rate, had to cease inviting individuals for periods while the pilot was running because colonoscopy services were unable to cope. 40 Australia does not appear to have monitored the impact of screening activities on routine colonoscopies in their pilot; however they have opted for staged implementation of their full programme to ensure that their colonoscopy capacity is adequate. 16,33

Identifying cancer—The positive predictive value (PPV) of the screening test varied between countries (from 5.2% in Australia to 14.3% in Italy). ^{10–17,28} Information on PPV is essential to inform participants about their chances of having cancer after a positive test. The variation between countries shows that locally relevant information is crucial.

The stage at which cancers were detected is an important surrogate indicator of screening programme success. ⁴¹ Screening should 'down shift' cancer stage when

compared to a stage at presentation in an unscreened population. The countries that reported stage had a majority of cancers in Dukes A or equivalent, suggesting that screening was detecting cancers earlier. 10,11,13,14,17

Lessons for CRC screening in New Zealand

This section highlights some of the areas that New Zealand will have to consider in the planning, design, implementation and evaluation of CRC screening. More thorough coverage of the issues, including quality considerations, is available elsewhere. ^{5,42}

Inequalities—Screening has the potential to exacerbate inequalities in health. In the studies reviewed here, there were differences in participation by sex, socioeconomic position, and age. ^{10–13,15}, ¹⁷ In the UK, the CRC screening programme was much less able to deliver a successful service to ethnic minorities along the entire screening pathway. This was reflected in lower participation rates, lower test completion, higher levels of psychological distress after FOBT, and lower uptake of colonoscopy after a positive result. ⁴³

Currently, in New Zealand, Māori are less likely to be diagnosed with CRC than non-Māori, but just as likely to die from it (i.e. Māori are less likely to survive CRC). For CRC, Māori are less likely to have stage recorded, less likely to have a localised stage at diagnosis, and more likely to be diagnosed at a later stage. ⁴⁴ Despite some progress, the New Zealand breast and cervical screening programmes have not yet achieved equitable screening rates between Māori and non-Māori. ^{44–46}

New Zealand CRC screening should be designed to both eliminate existing inequalities in CRC (e.g. in stage at diagnosis) and avoid creating new inequalities. This will require these goals to be explicitly integrated throughout all levels of the planning and activity and evaluation. It will require strong leadership and commitment to these goals.

Ensuring adequate participation—Ensuring adequate participation in CRC screening will be one of the key challenges in New Zealand. A vital part of this is the ability to identify eligible people and invite them to participate in screening. Participation in CRC screening pilot studies was, in the main part, modest despite all countries using population based registers. The evidence of population benefit comes from trials where 60–75% of individuals invited participated in screening at least once.³

Recommendations that New Zealand should develop and utilise a population register to invite people to participate in screening have been made on many occasions. It is essential that a register is developed and trialled in a CRC screening pilot — possibly based on Primary Health Organisation enrolment data which covers the majority of the population. 151

Choosing a screening test—The CRC screening advisory group recommended that a feasibility study be conducted using FOBTi. There are obvious advantages to FOBTi, including increased sensitivity, the ability to determine the 'positive threshold', and the ability to automate processing, which could improve quality control.^{5,18}

In addition, there is some evidence suggesting that participation may be better with FOBTi, although it is difficult to know how to interpret this as there was no difference in participation in the pilot studies that used FOBTi. ^{19,20} On the other hand, the disadvantages are higher cost—lack of RCT evidence of a mortality benefit and the potential for very high positivity rate which could overwhelm health services due to colonoscopy demand.

Several jurisdictions have selected guaiac tests because of their lower positivity rate and thus requirement for fewer colonoscopies, ^{10,39,52} and it is difficult to see how NZ could cope with a positivity rate similar to that seen in Australia. For example, in Waikato DHB in the 2006 census, there were approximately 70,000 men and women aged 50–70. Assuming a 60% participation rate in screening, using an FOBTi with 9% positivity, an extra 3780 diagnostic colonoscopies would be required over 2 years for a prevalence round of screening. In contrast, a 1.9% positivity rate would result in about 800 extra colonoscopies being needed.

Service capacity—As with other countries developing CRC screening, colonoscopy capacity is probably the biggest challenge for New Zealand to implement CRC screening. A survey of endoscopy units conducted in 2005 indicated that many services could not offer diagnostic colonoscopy to symptomatic patients within 3 months of referral.⁵³ If services are not currently able to offer timely colonoscopy to those with symptoms, then the increased demands of a screening programme are very likely to compromise the already stretched diagnostic services. Options for increasing service capacity, such as training health professionals other than doctors to perform endoscopy, will need to be explored. It may also be necessary to restrict the age range to which screening is initially offered (for example to 60–69 as has been done in England⁵⁴) and then look to increase this later as capacity allows.

Information systems—Information systems for a feasibility study are vital in assuring the optimal and ethical delivery of screening activities. Without such systems it is impossible to ascertain how much benefit, or otherwise, a screening programme is providing at a population level or to ensure adequate safety net provisions for individual participants. For example, in the Australian pilot, 45% of screen positive participants were 'lost to follow up', highlighting the potential consequences of inadequate information systems.^{15,16}

Similar problems were faced by the groups evaluating the breast cancer screening pilots in New Zealand, where changing data systems and the lack of centralised access to data made evaluation difficult. The Gisborne Inquiry also highlighted problems with correlation of histology and cytology information and the lack of centralised information in the New Zealand cervical cancer screening programme. Setting up good information systems is a vital foundation for a functional screening pilot study and programme.

High-risk individuals—There are two areas to consider in relation to high-risk individuals and groups, firstly services for those already at high risk of CRC and thus not eligible for population screening and secondly those who become 'high risk' after participating in screening (e.g. through detection of high risk adenoma).

Careful consideration has to be given to individuals and groups who are already at high risk of CRC (e.g. through personal or family history). Currently, there are

clinical guidelines recommending the regular surveillance and monitoring of this group, but there is evidence that not all public hospitals are able to offer the recommended level of service. ^{53,56}

Individuals who have high-risk adenomas detected through screening are no longer eligible for population-based screening, which is aimed at people of 'average' risk. In the UK, people who become 'high risk' after participating in screening are then managed in a specific arm of the screening programme, allowing better assessment of surveillance colonoscopy requirements and providing them with best practice management. ³⁹ This approach should be adopted in New Zealand.

Conclusion

New Zealand, like many other countries, is exploring CRC screening as a way to reduce mortality from CRC. Like other population-based screening programmes, CRC screening is expensive, complex, and demanding. Learning from international experiences is one way that we can minimise problems in planning and delivering screening. Additionally we need to heed the lessons from the New Zealand experience of implementing cervical and breast cancer screening programmes- they remain germane.

Competing interests and acknowledgement: The authors received funding from the Ministry of Health to provide advice on aspects of a colorectal cancer screening programme. The views expressed in this paper do not necessarily reflect those of the Ministry of Health.

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NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716

URL: http://www.nzma.org.nz/journal/121-1279/3186/

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THE NEW ZEALAND MEDICAL JOURNAL

Journal of the New Zealand Medical Association



Primary gastric mucosal melanoma

Joseph Yuan-Mou Yang, Govind S R Krishna, Collin MacLeod, Willem Oosthuysen

Melanoma is a highly malignant neoplasm that commonly arises in skin but primary melanoma can infrequently arise from the mucosa of the gastrointestinal tract. Primary gastric mucosal melanoma (PGMM), in particular is a rare clinical phenomenon.¹

To our knowledge, we are documenting the first reported case of PGMM from New Zealand and the eighth in the world.

Case report

We report a 53-year-old Caucasian male admitted to Whangarei Hospital with recurrent epigastric pain, weight loss, and recent onset of dysphagia. On clinical examination a hard non-tender epigastric mass was felt. Laboratory investigation confirmed microcytic hypochromic anaemia. Gastroscopy showed a large, darkpigmented growth, at the gastro-oesophageal junction. Biopsies confirmed malignant melanoma.

CT scan chest and abdomen revealed a large intra-luminal mass involving the gastrooesophageal junction. The tumour was abutting against pancreatic body. There was regional lymphadenopathy (Figure 1).

Figure 1. Contrast CT scan showing a large intra-luminal gastric mass with associated lymphadenopathy. The mass is also adhering to the pancreatic body and tail and also to part of the transverse colon



Colonoscopic examination revealed no anorectal or colonic primary melanomas. Similarly, dermatological, ENT and ophthalmologic examinations did not reveal any other primaries. A brain and spine MRI performed also ruled out any CNS lesions. Patient had no prior history of removal of atypical skin lesions.

The patient underwent oesophago-gastrectomy via right sided thoracotomy, and laparotomy. A large pigmented gastric oesophageal junction tumour was resected. Corresponding regional lymphadenectomy with distal pancreatectomy, splenectomy, and transverse colectomy were performed after palpable suspicions of tumour extension to these sites.

Histologically tumour was a malignant melanoma. There was no evidence of lymph nodes metastasis or of tumour extension to the pancreas or transverse colon. Resection margins were clear of the tumour.

The postoperative course was complicated with small bowel infarction. Segments of ischaemic bowel were resected and a double-barrelled loop ileostomy was created. Ileostomy was reversed once the patient stabilized. Patient deferred any other interventions and accidentally died 11 months postoperation.

Discussion

This patient presented to us with solitary malignant melanoma of gastro-oesophageal junction with no previous or present history of cutaneous melanoma. Additionally extensive investigation of other known sites of primary melanomas did not reveal any other primary. The diagnostic criteria of PGMM quoted includes absence of concurrent lesions and no history of removal of melanoma or atypical melanocytic lesions from skin or other organ.^{2–7}

Gastric melanoma is more commonly presented as a metastatic secondary from cutaneous sources. Some literatures have reported spontaneous regression of these cutaneous primaries. Although we acknowledge this as a plausible explanation to our case's presentation, the absence of relevant history made this diagnosis less likely than PGMM.

PGMM is an extremely rare form of neoplasm. About 4–5% of all primary melanoma arise from extracutaneous source. Only about 1% of these were found to be mucosal in origin, including sites such as digestive, respiratory, and genitourinary tracts. ^{2,3}

All case reports of PGMM were male in gender and have a mean diagnosis age of 60.^{2,4–8}

Anaemia and weight loss have been most commonly described. Others include a constellation of symptoms, such as nausea, vomiting, and abdominal pain. Endoscopy and barium contrast radiography are both reasonable conventional initial diagnostic approaches. The presence of pigmentation of an ulcer is the most common endoscopic finding. ^{2,5} CT scan of abdomen and chest may reveal evidence of lymph node metastasis. Tissue sampling provides the definitive diagnosis. Immunohistochemical staining with S-100 and HMB-45 has increased the diagnostic sensitivity of the biopsy and cytological evaluation. ^{2,9,10}

Due to the limited knowledge of PGMM, no survival data has been published. Mucosal melanoma seems to be more aggressive and associated with a poorer

prognosis than cutaneous melanoma due to delay in diagnosis, inherently more aggressive behaviour and early dissemination. ^{11–18}

Surgical resection continues to be the mainstay of primary therapy. Considering local recurrences and survival, local excision has been shown to be equal to radical surgery. Like cutaneous melanoma, gastrointestinal malignant melanoma is thought to be radio-resistant. ¹⁹ The data on chemotherapy is too sparse to draw any valid conclusion.

PGMM is a rare condition associated with delayed diagnosis, poorer prognosis and need for surgical resection as a mainstay treatment.

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THE NEW ZEALAND MEDICAL JOURNAL Journal of the New Zealand Medical Association



The escape artist! Detecting choroidal metastases in the setting of breast cancer

Christolyn Raj, Gary Leber

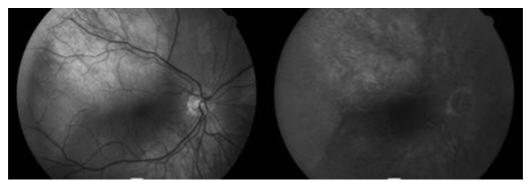
Choroidal metastases (CM) represent the smallest detectable lesion of systemic dissemination of breast cancer in the body. However it often escapes diagnosis because of its frequent asymptomatic presentation or the dominant picture of metastatic disease occurring in other organs.

Early detection and radiotherapy treatment can achieve tumour regression and symptom resolution thereby improving the patient's quality of life.

Figure 1. Active CM lesions



A) CM lesion from breast cancer showing peripheral, yellow, plateau-shaped lesion. B) CM lesion in lower right quadrant causing serous retinal detachment.



C) CM lesion in upper temporal quadrant of RE as seen on a fluorescein angiogram. White colouration indicates contrast extravasation from choroidal blood vessels.

Case report

A 52-year-old woman with breast carcinoma with pulmonary and cerebral metastases presented with a 4-week history of worsening blurred vision in the right eye. She denied symptoms of headache, visual scintillations, and floaters in her visual field or any motor or sensory disturbances. Her uncorrected distance vision was count fingers (CF) at 1 metre. Her best corrected distance vision was 6/12 at 6 meters. Initial ocular fundus examination was unremarkable. A CT brain showed four small cerebellar lesions (largest 7mm) consistent with cerebral metastases.

A subsequent fluorescein angiogram showed a superior quadrant choroidal metastases. She received treatment for this symptomatic CM with external beam radiotherapy (EBRT) to the right eye, a total of 20Gy in 5 fractions. At 2 months follow-up, her blurred vision had subjectively improved though she still required a spectacle correction (+2.00 DS) to reach distance visual acuity of 6/6.

Discussion

The estimated prevalence of CM from breast carcinoma ranges from 5–9%. Breast and lung carcinoma together account for 71 to 92% of CM.¹ On average, CM occurs 3 years following diagnosis of the primary malignancy.² Typical symptoms include rapid onset of blurred vision (days to weeks), floaters in the vision, and/or visual field loss.

The key features of a CM from breast carcinoma are a solitary, yellow-coloured, plateau-shaped lesion that may be associated with retinal elevation. Differentials for a coloured retinal lesion which should be considered include metastases from melanoma or carcinoid tumour.

However in some atypical cases such as this case a CM lesion may not be easily discernable on an ocular fundus examination and requires a fluorescein angiogram. In common ophthalmic practice, an ultrasound B scan of the orbit is preferred over CT or MRI to confirm CM.

Some studies have highlighted the presence of CNS metastases occurring concurrently or shortly after the diagnosis of CM.^{3,4} Could the diagnosis of CM therefore herald the existence of yet undetected metastatic lesions within the CNS? In light of this it seems prudent that patients with a newly diagnosed CM lesion also undergo re-staging of their disease status prior to any treatment planning.

EBRT is the mainstay of treatment for symptomatic CM and has been shown to promote tumor regression in 63-83% of cases. ⁵⁻⁷ A total dose of 21-50Gy has been advocated to achieve tumor regression. With respect to visual outcome, in a large case series 27–89% of patients had improved visual acuity post radiotherapy.

In 57–100% of patients their visual acuity was either improved or stabilized. Vision-threatening side effects (cataracts, retinopathy) occur at doses greater than 40Gy. However the strength of the radiation dose and the ultimate decision regarding treatment modality depends on the presence of co-existent cerebral metastases at the time of diagnosis of CM.

The choices therefore become localised EBRT or whole brain radiotherapy. ¹⁰ CM has been shown to respond to chemotherapy however randomized trials in this area are lacking.

The finding of CM is indicative of end-stage disease.¹¹ However up to 10% of patients with untreated CM survive more than 5 years. A symptomatic CM lesion if diagnosed and treated in a timely manner can improve the quality of life of these patients.¹²

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Acknowledgements: The authors thank the Department of Retinal photography at the Royal Victorian Eye and Ear Hospital for their assistance in providing the retinal photographs used in this case report.

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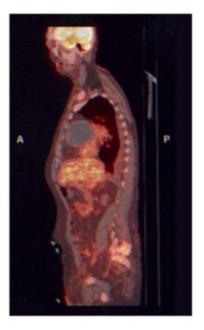
Mediastinal mass in a patient with coronary artery disease

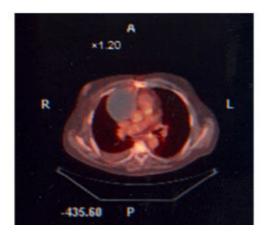
Amer Zeidan

A 66-year-old male with history of coronary artery disease status post coronary artery bypass grafting in 1992 was found to have a large mediastinal mass noted incidentally in a chest X-ray. No prior imaging studies were available for comparison. A non-contrasted CT scan of the chest showed a 7.5×8.5 cm homogenous, right anterior mediastinal mass contiguous with the ascending aorta. Subsequently, a contrasted CT scan of the chest was done and showed the mass to be nonenhancing.

Figure 1. Positron emission tomography (PET) images demonstrating the large spherical mediastinal mass







A left-sided heart catheterisation showed 100% occlusion of the saphenous vein graft to the right coronary artery, while the mass was not visualised. A positron emission tomography / computed tomography (PET/CT) scan was done 2 weeks later (shown in Figure 1) and detected no abnormal uptake within the mass to suggest malignancy and no evidence of lymphadenopathy. The mass was most consistent with a thrombosed aneurysm of the saphenous vein graft to the right coronary artery.

It was decided to observe the patient, given the high risks of surgical intervention.

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THE NEW ZEALAND MEDICAL JOURNAL



Journal of the New Zealand Medical Association

CT colonography for colovesical fistula

Andrew Ing, Andrew Lienert, Frank Frizelle

A healthy 65-year-old male presented with a 5-day history of pneumaturia and urinary frequency. He had no symptoms suggestive of systemic infection, there was neither weight loss nor change in bowel habit. Two years previously he had CT confirmed sigmoid diverticulitis. The patient was tender both suprapubically and in the left iliac fossa. Rectal examination was unremarkable. Laboratory tests demonstrated no evidence of anaemia nor neutrophilia. There were coliforms in the urine.

CT colonography (CTC) confirmed the diagnosis of colovesical fistula secondary to diverticular disease. CTC allows excellent views and with air in the bladder allows demonstration of the fistula. Often when colonoscopy is attempted to assess the colonic lumen it fails due to angulations and distortion associated with the fixation to the bladder. In addition, it does not demonstrate the anatomy of the fistula.

We believe that CTC provides a superior assessment of this fistula. The patient underwent an elective sigmoid colectomy with colorectal anastomosis with fistula repair 6 days later. Up to 60% of colovesical fistulae are related to diverticular disease; however malignancy should where possible be excluded.

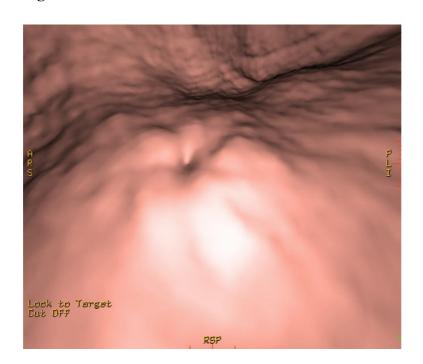


Figure 1. CTC reconstruction of the bladder side of the fistula

Figure 2. CTC reconstruction of the colonic end of the fistula

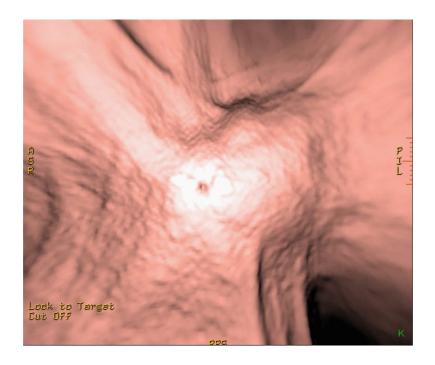


Figure 3. CTC demonstrating air through colon and in bladder

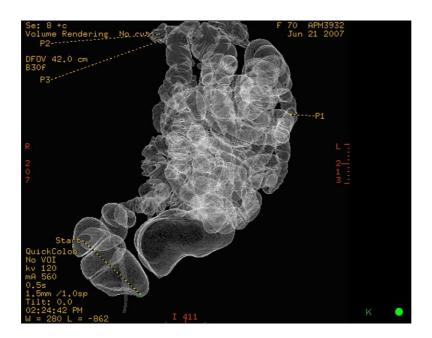


Figure 4. CTC with fistula tract marked

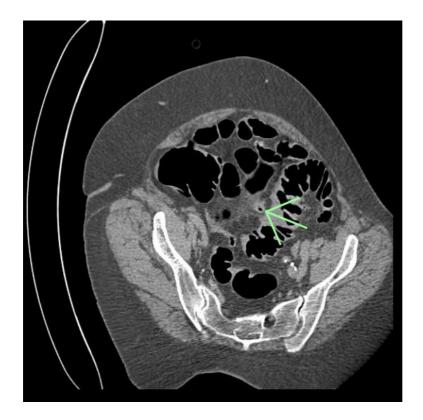
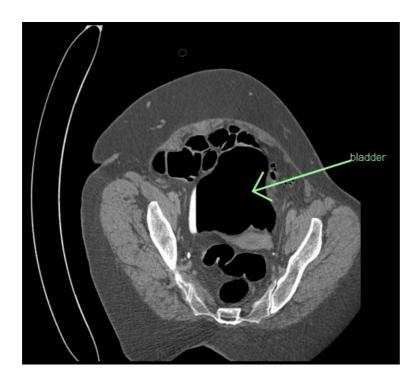
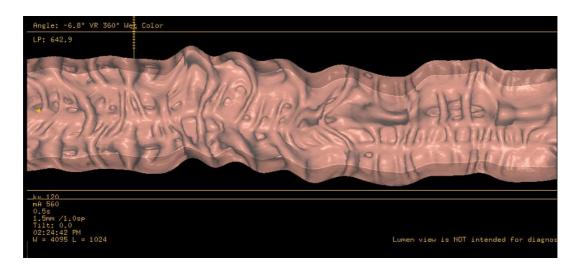


Figure 5. CTC with bladder with air in it marked



NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1279/3199/

Figure 6. CTC with opened view of colon



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THE NEW ZEALAND MEDICAL JOURNAL Journal of the New Zealand Medical Association



Registrars for collecting information at the main hospitals

Editorial published in N Z Med J. 1909;7(31):32–33.

THERE is one matter in connection with our public hospitals on which we believe all the doctors in New Zealand are agreed, and that is, that an enormous amount of clinical material is yearly going to waste.

These remarks do not apply with quite so much force to the Dunedin Hospital, for there the presence of a medical school necessitates clinical lectures, and clinical lectures imply working up of cases to a certain extent; but even there the system admits of great extension. Important operations are done daily in all the large centres, but the patient, the operator and his assistants are the only ones who know anything of them. New methods of treatment are devised, individual experience is gained, but the doctors of the dominion do not benefit; each one has to learn for himself; there is no attempt to collect information for the general good.

The result is, this JOURNAL, which should be a means not of bringing this or that operator into prominence but of recording all that is best out of the mass of work done, has to depend for its supplies on the industry of a few. The medical superintendents of our large hospitals are not to blame for this; they have already more work to do than should fairly be put on the shoulders of any man, and the proper collation and analysis of the cases that go through their hands cannot be done by them. What is wanted is this, and we desire most earnestly to bring the matter to the notice of all who are interested in the management of our hospitals, *Registrars ought to be appointed in each large centre*.

The Registrar must of course be a doctor, and he should be a man of liberal ideas, with an enthusiasm for his work; he should be willing to devote at least one hour every day to the hospital, he should be present if possible at all the important operations, and at post-mortems in cases of special interest. No man could be expected to undertake these arduous, though most interesting and informing duties for nothing; therefore, he should be paid a salary. It would be little enough to ask that a small extra fee should be paid by each in-patient to cover the cost of a full description of his case for future reference. Apart from the good it would do to doctors and so indirectly to the patients, who would benefit by the experience gained by the doctors, it would also benefit any patients who might have to again become inmates at some future date.

In fact, the arguments for the appointment of a Registrar are numerous and unanswerable. The only questions are: Can suitable doctors be found for the post, and can the necessary salary be found? We think both these questions can be answered in the affirmative.

[Since writing the above we have heard on good authority that in all probability the Honorary staff of the Dunedin Hospital will appoint from their own number a medical and surgical registrar, whose duties will be, *inter alia*, to furnish quarterly hospital reports to the JOURNAL. We need not add we have heard this with the greatest satisfaction and hope the other large hospitals will follow suit.]

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716

URL: http://www.nzma.org.nz/journal/121-1279/3183/

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Hormone replacement therapy and breast cancer incidence both decline

The Women's Health Initiative trial—comparing combined hormone replacement therapy (HRT) with placebo—showed a significant increase in the risk of breast cancer, coronary heart disease, venous thromboembolism and stroke among women using HRT. As expected, HRT use subsequently declined, but what else happened? After the report was published in 2001, the incidence of breast cancer in US women aged 50 years or older dropped by 11% between 2001 and 2004.

HRT use tends to increase the risk of oestrogen receptor (ER)-positive tumours, and the fall in breast cancer incidence in the US after 2001 was largely confined to ERpositive tumours.

This paper reports on the Australian situation—a 6.7% fall in age-standardised incidence of breast cancer in Australian women aged ≥ 50 years in 2003 compared with 2001. The authors estimate that this equivalent to 600 fewer cases in this age group (out of a total of about 9000).

MJA 2008:641-4

Different regimens to lower blood pressure versus the age of the patient

It is widely believed that blood pressure levels are strongly and directly related to the relative risks of stroke and heart disease but that the strength of the association declines with increased age. This meta-analysis from Australia sets out to examine these hypotheses. No less than 31 trials, with 190,606 participants, were included in the systematic review. Approximately half of the patients were 65 years of age or older and the gender mix was about equal.

And the conclusions were that blood pressure reduction produces similar proportional reductions in the risks of vascular events in younger (<65 years) and older (≥65 years) adults. And there was no clear evidence to support recommendations for particular drug classes in older or younger adults.

BMJ 2008;336:1121-3

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Treatment of group A β-haemolytic streptococcal pharyngitis

Eradication of this organism is recommended because of its possible sequela rheumatic heart disease. In the past this was achieved with a single intramuscular dose of long-acting penicillin and more recently with a 10-day course of penicillin V orally in 2 or 3 divided doses. Difficulties with compliance and the need to take it 1 hour before food mar its effectiveness.

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In this report from Auckland the conventional oral penicillin treatment has been tested in a randomised trial with a single daily dose of amoxicillin (750mg-1500mg depending on the weight of the child).

353 children were involved and the once daily amoxil was found to be not inferior to twice daily penicillin V, both in curing the pharyngitis and eradicating the streptococcus.

Arch Dis Child 2008;93:474-8

Intensive blood glucose control in type 2 diabetes

Two papers in a recent *NEJM* address this proposition. In one, patients with type 2 diabetes who had either established cardiovascular disease or additional cardiovascular risk factors were randomised to receive intensive therapy (targeting a glycated haemoglobin level below 6.0%) or standard therapy (targeting a level from 7.0% to 7.9%). Unexpectantly, the use of intensive therapy to target normal glycated haemoglobin levels for 3.5 years increased mortality and did not significantly reduce major cardiovascular events. An editorial commentator wonders whether such intense treatment would benefit the majority of type 2 patients who do not have high cardiovascular risk factors.

The other paper goes some of the way to answer this, as it reports on a less selected group in its trial—lowering the glycated haemoglobin value to 6.5% yielded a 10% relative reduction in the combined outcome of major macrovascular and microvascular events, primarily as a consequence of a 21% relative reduction in nephropathy.

N Engl J Med. 2008;358:2545-72 & 2633-5

Gastrointestinal bleeding after percutaneous coronary intervention (PCI)

Bleeding has now emerged as one of the most common complications after PCI—its incidence ranging from 3–9% in various reports.

The site of bleeding is most frequently related to the femoral access site (52–73% of events). However a significant minority of bleeds, unrelated to arterial access, occur including GI bleeds, intra-cerebral bleeds and large haemoglobin drops without a clinically obvious bleeding site.

The need to prevent restenosis is paramount hence the use of low-dose aspirin and clopidogrel. On the other hand, these drugs are clearly culprits in the bleeding issue. In this meta-analysis the focus is on gastrointestinal bleeding and how to prevent it. Prophylactic usage of proton pump inhibitors is supported by trial evidence because of its gastroprotective effect but does not help prevent lower gastrointestinal bleeding.

Q J Med 2008;101:425–33

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Use of title 'Dr'—view of the Medical Council of New Zealand

In the 25 July 2008 issue of the *New Zealand Medical Journal* there was a very interesting article by Dr Andrew Gilbey entitled *Use of inappropriate titles of New Zealand practitioners of acupuncture, chiropractic and osteopathy* (http://www.nzma.org.nz/journal/121-1278/3160). This has been an issue of concern to the Medical Council of New Zealand, and over the past few years we have written to a number of non-medical practitioners who have used the title 'Dr' inappropriately.

We are careful when we do this, however, because it can be a grey area. Many non-medical people are fully entitled to use the title if they hold a university doctorate. Our concern is not so much about when people use the title 'Dr', it is when they do so in a manner which has the potential to mislead patients into believing that the person is a medical practitioner.

In his article Dr Gilbey suggests that the Council should make the New Zealand Yellow Pages aware that their current practice of allowing non- doctors to use the title 'Dr' is legally dubious.

The Council has been engaged with the publishers of our phone books on this issue for some years. Historically we had an agreement with Telecom regarding the *Registered Medical Practitioners* section at the front of the White Pages. Under this agreement, we provided Telecom with a list of registered medical practitioners so they could check that any person listed in this section was registered with the Council. Unfortunately, Telecom withdrew from this agreement without consultation or prior notice in 2007.

Subsequently the White and Yellow Pages were sold to the Yellow Pages Group. We wrote to the Yellow Pages Group in July 2007 outlining our concern that the practice of checking against the register appeared to have ceased. We specifically drew their attention to section 7 of the Health Practitioners Competence Assurance Act 2003. Furthermore, we suggested that the listing of an unregistered doctor in the Registered Medical Practitioners section of the White Pages could be considered a breach of the Act.

The Yellow Pages Group failed to respond to this letter and the practice of listing 'Drs' without reference to the register continued. Two further letters were sent to the Yellow Pages Group, the last letter containing a list of people who we discovered were listed in the 'Registered Medical Practitioners' page but who were not registered doctors.

In response to our final letter, the Yellow Pages Group advised that it would remove the word "Registered" from the heading of the section at the front of the White Pages and the words "All doctors listed in this section must be on the New Zealand Medical Register". However, they also stated that they are "...unable to check the veracity of every listing and advertisement in our directories. Instead we accept advertising in

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1279/3206/ good faith and we rely on our advertisers' assurances that their advertising complies with all laws (including the Health Practitioner Competence Assurance Act 2003)."

We agree with Dr Gilbey that the practice of allowing non-doctors to advertise using the title 'Dr' is legally dubious and we have already alerted the Yellow Pages Group to this issue.

However, Council is not empowered to prosecute breaches of this section under the Health Practitioner Competence Assurance Act 2003. This power is provided to the Ministry of Health. Accordingly, we have forwarded a copy of Dr Gilbey's article, this letter and our previous correspondence with the Yellow Pages Group to the Ministry for their consideration.

Simon Robb Registrar Medical Council of New Zealand Wellington



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Journal of the New Zealand Medical Association

Abuse of the title 'Dr'

In a recent article on the use of the title 'doctor' by complementary and alternative medicine (CAM) practitioners, Andrew Gilbey makes the following recommendation: "that CAM practitioners who are not medically registered practitioners must accept that in New Zealand they are not entitled to use the courtesy title 'Doctor' and cease to do so at the earliest available opportunity". 1

In an editorial commenting on this, David Colquboun states that the title of doctor is "widely abused", and later states that "You can still be held to have misled the public into thinking you are a medical practitioner, even if you have a real doctorate".²

As such, a real doctor is in danger of being prosecuted in order to protect the professional turf of those who use the title as a 'courtesy'. Perhaps it is time that we left this topsy turvy Wonderland world and brought in regulations so that only those who have 'real' doctorates should be allowed the title of doctor. It is clear that the medical profession itself has been abusing the title for some centuries.

Professor Kevin Dew School of Social and Cultural Studies Victoria University of Wellington Wellington

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- Colquhoun D. Doctor Who? Inappropriate use of titles by some alternative "medicine" practitioners. New Zealand Medical Journal. 2008;121(1278). http://www.nzma.org.nz/journal/121-1278/3158

Response from Andrew Gilbey

In principle, Professor Dew's reflection on who is truly entitled to use the title doctor is correct. Only those conferred doctorates from recognised universities do not mislead if they use the title of doctor. (Obviously, this precludes those who have bought, rather than earned, their 'doctorates', as identified by Professor Colquhoun.)¹

In practice, however, the title 'doctor' is synonymous with 'registered medical practitioner'. To argue its use should be discontinued, on the grounds that it is wrong in principle, would divert attention from where its use is abused. Indeed, I suspect that registered medical practitioners gain little by using the title doctor, whereas prospective clients gain much by being helped to identify who is a registered medical practitioner and who is a complementary and alternative medicine (CAM) practitioner.

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1279/3202/ Conversely, CAM practitioners, who are not registered medical practitioners, gain much by using the title doctor (e.g. competitive advantage, social-status, credibility). And herein lays the problem identified in my recent article. When used by CAM practitioners, the title doctor may mislead prospective clients by making it harder for them to differentiate between providers of mainstream medicine (which is evidence-based and theory-driven) and CAM (which is often supported by anecdotal evidence and has little or no theoretical rationale).

Ever the pragmatist, I suggest that New Zealand's legislation, as interpreted in the Medical Council News, is pitched sensibly.³ But, like the equally sensible 20 km/h speed limit for driving past New Zealand school buses as they unload, such legislation is of little use if it neither adopted nor enforced. I therefore reiterate that current legislation should be enforced. That is, registered medical practitioners call themselves doctor and all other health practitioners refrain from using the title doctor unless they have doctorates directly relevant to their area of practice. Those with doctorates should make clear the area of their doctorate if it is not in medicine or their area of CAM practice.

Andrew Gilbey Lecturer College of Business Massey University Palmerston North, NZ

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- 3. Medical Council News; The right to the title 'doctor'; Wellington, NZ Medical Council of New Zealand. 2006;42(5).

Response from David Colquhoun

While sympathising with Professor Dew, I fear he is too late. There are two reasons for this. The first is that the popular use of the word 'doctor' to mean a medical practitioner, that one can't imagine it ever being replaced. As consequence its use by people with real doctorates in a medical context can easily be misleading and therefore wrong. Most PhDs that I know use their titles only in an academic environment (or to impress a bank manager).

A more important reason is that as an academic title "doctor" has been made almost worthless, by things like awarding 'doctor of chiropractic' as first degrees (I'm told that 'doctor of physiotherapy' is also being considered in New Zealand). These involve no research at all.

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If we were to follow Professor Dew's advice, the effect that chiropractors with one of these degrees could call themselves 'doctor' quite legitimately. Still worse, it would give a boost to the mail-order doctorates like that of "Doctor" Gillian Mckeith.

The blame for this absurd situation lies squarely with university vice chancellors and principals, and with government officials (with the HR-mindset) who seem happy to prostitute intellectual standards by handing out doctorates to almost anyone for fees.

David Colquhoun Research Fellow Dept of Pharmacology University College London, UK

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Journal of the New Zealand Medical Association

The International Study of Asthma and Allergies in Childhood

Dear Professor Frizelle

Further to our letter of February 2003, we are writing to you, and other Editors, to explain the use of the acronym ISAAC (International Study of Asthma and Allergies in Childhood) in publications submitted to Journals. Our website (http://isaac.auckiand.ac.nz/) provides more detail about ISAAC.

We appreciate the opportunity to publish the results of ISAAC in medical and scientific journals. However, our concern is that some centres outside the ISAAC collaboration are posing as genuine ISAAC centres by including ISAAC in the title of submitted manuscripts and even alluding to being bona fide ISAAC centres. We wish to draw this to your attention.

We recognise your right to publish whichever manuscripts you consider appropriate. However, if the ISAAC name is used indiscriminately, this could undermine the true value of ISAAC. We would therefore like to clarify the ISAAC publications policy as determined by the ISAAC Steering Committee.

ISAAC Phase One involving 156 centres in 56 countries has been completed, resulting in many publications (see http://isaac.auckland.ac.nz/).

ISAAC Phase Two involves 30 centres in 22 countries. Papers for publication are being submitted at the present time.

ISAAC Phase Three involves 233 centres in 97 countries. Papers for publication are being submitted at the present time.

Publications resulting from bona fide ISAAC collaborating centres are entitled to include ISAAC in the title of the manuscript, but our policy is that others are not, because this would be potentially misleading to the scientific community.

The ISAAC Steering Committee endorses as an "ISAAC" study only those whose data has been processed and accepted at the appropriate ISAAC Data Centre (Ulm, Germany, for Phase Two and Auckland, New Zealand for Phases One and Three). If other studies use ISAAC instruments, we are happy for this to be acknowledged in the methods section of the article, but these are not "ISAAC" studies, and ISAAC must not be included in the title of these publications.

NZMJ 8 August 2008, Vol 121 No 1279; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1279/3184/ ISAAC Collaborators are aware that analyses of several ISAAC centres may be published subject to the following approvals:

- 1. Comparisons of 2 or more ISAAC studies within a country need to be approved by the ISAAC National Coordinator for that country.
- 2. Comparisons of 2 or more ISAAC countries within a region need to be approved by the ISAAC Regional Coordinator for that paper.
- 3. Comparisons of 2 or more ISAAC regions need to be approved by the ISAAC Steering Committee.

These processes have been developed to respect and protect the integrity of the data of individual ISAAC collaborators, and the scientific reputation of ISAAC.

If you require any clarification of the situation or have any queries about particular papers, please do not hesitate to contact me or one of the ISAAC Executive listed below:

Professor Innes Asher, Chair mi.asher@auckland.ac.nz
Professor Neil Pearce n.e.pearce@massey.ac.nz
Professor David Strachan d.strachan@sghnis.ac.uk

Professor Luis Garcia Marcos <u>lgmarcos@um.es</u>



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Journal of the New Zealand Medical Association



Undergraduate education to address patient safety

Errors in healthcare delivery are a significant and widely acknowledged problem, both in New Zealand and worldwide. At Capital and Coast District Health Board we investigate critical incidents and serious adverse events so that organisational learning can take place to prevent recurrence. During one such investigation, a fixation error was identified as being contributory. By this we mean a pattern of error, characterised by the persistent pursuit of an initial and incorrect diagnosis, despite subsequent disconfirming evidence. This pattern of error is not uncommon and arises when the practitioners are biased by some feature of the initial clinical context. 3

In their report, the reviewing clinicians recommended a series of system-based improvements to improve the detection and prevention of future errors. The recommendations were supported by the office of the Health and Disability Commissioner, and specifically included a commitment to encourage Medical and Nursing Schools in New Zealand to include error-related education in their undergraduate curricula.

Our first step in this process was to survey the Medical and Nursing Schools to enquire about their level of error-related education, and to offer to help with the coordination and development of an undergraduate curriculum to address error and potential countermeasures. We sent questionnaires to 20 nursing and medical schools in New Zealand, and received 14 replies (70%).

One institution reported that they did not provide any error-related education, and the remaining thirteen described some form of error-related or quality assurance education. This included at least a one-hour lecture and a range of opportunistic educational experiences across the clinical curriculum. Seven of the responding institutions expressed an interest and willingness to collaborate in the development of a shared curriculum. The Faculty of Medical and Health Sciences, University of Auckland provided us with a copy of the program for their two-day inter-professional "Quality and Safety" learning module. This formal and structured approach to human factors in healthcare, with focussed error education, is mandatory for their third year students from medicine, nursing and pharmacy. We think that their approach is exemplary, not only because of the importance of error and its consequences, but also because an interdisciplinary approach provides implicit training for clinical teamwork.⁴

The primary purpose of the recently launched "National Policy For The Management Of Healthcare Incidents" is to "learn from experience and improve systems and processes in healthcare". This Policy includes significant emphasis on education, but with a focus upon the Health and Disability Services. Although an educational focus at the Health and Disability Services level will add to what has already been achieved in specialties such as anaesthesia and surgery, it will not address undergraduate education.

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URL: http://www.nzma.org.nz/journal/121-1279/3203/

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The need for effective undergraduate education regarding human factors and medical error has been recognized for a number of years, ⁸ and several authors have described curricula that provide effective undergraduate education regarding the ubiquitous nature of error in healthcare, the need for effective error reporting, and for systems to trap and then deal with the consequences of error in healthcare, including disclosure to the patient and their families. ^{4,9,10}

We believe that undergraduate education in human factors and error should be mandatory, and the Auckland approach could form the basis for a mandatory national curriculum, similar to the New Zealand Medical Council requirement of Advanced Cardiac Life Support certification, for provisional registration. Such an undertaking would require significant collaboration and cooperation amongst a large number of tertiary education providers and our survey suggests that there is willingness for cooperation of this sort to take place.

Alexander Garden Associate Professor and Clinical Associate Director Sleep Wake Research Centre Research School of Public Health Massey University Wellington

Specialist Anaesthetist Capital and Coast District Health Board Wellington South

Sharmila Bernau Clinical Auditor

Geoffrey Robinson Chief Medical Officer

Cheyne Chalmers
Director of Nursing and Midwifery

Capital and Coast District Health Board Wellington South

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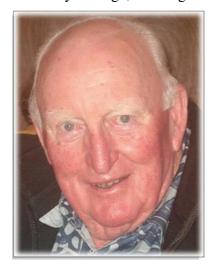


Journal of the New Zealand Medical Association

Richmond (Geoff) Kjestrup

F/O RAFVR 2608805; 18 December 1926-13 July 2008

Geoff was born in Masterton and attended primary school at Whangahu, Masterton. His first 3 secondary school years were completed by correspondence, and he attended Hawera High School. Medical Intermediate was completed at Victoria University College, Wellington.



As all places at Otago Medical School were taken by returning servicemen, Geoff applied to every Medical School in the UK whereby he was accepted at Liverpool University.

At University his love of flying was established. He joined the University Air Squadron, became an officer, and after qualifying from Med School he became the Medical Officer of the squadron.

In 1957, Geoff returned to New Zealand, working his passage as the ship's Doctor. Upon his return he went to Huntly and established his General Practice where he practiced for 30 years. He became a very busy GP with a special interest in Obstetrics.

He was involved in many of the usual small-town activities—school committees, foundation member of Jaycees and the squash club, board member of the Kimihia Home for the Aged, medical officer for the rugby club, and medical advisor to Plunket.

He had many interests, particularly boating, fishing, water skiing, squash, golf, and travel. In 1985 Geoff decided to retire from his practice is Huntly and move to Omaha Beach permanently. Over the next 10 years, he was active in locum work in the surrounding northern areas.

He continued to enjoy his retirement in good health, swimming, golfing, fishing, and following the progress of his grandchildren through their education and sporting interests.

Geoff is survived by his wife Lorna. Loved father, father-in-law of Eric, Sal, Alex, Fraser and Steph; Lynne and Matt Lind, Henry, Sam and Tanner; and Graham and Eileen, Lauren, and Everett (Los Angeles)

This obituary was written by Geoff's son, Graham.

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Colin Murdoch

Inventor (6 February 1929–4 May 2008)

One of New Zealand's most significant inventors has died.

Colin Murdoch the creator of the disposable syringe, the tranquilliser gun, the childproof bottle cap, and the silent burglar alarm died recently after a long battle with cancer.



Mr Murdoch was born in 1929 in Christchurch, but for more than 50 years lived in South Canterbury.

He was a pharmaceutical and veterinary chemist as well as an inventor.

Working late at night at the kitchen table or in his workshop Mr Murdoch was to patent 46 inventions.

He became a self-taught engineer.

His most famous and influential invention for the wellbeing of humankind was the disposable syringe which he developed more than 50 years ago.

The catalyst for this invention was as a young pharmacist he became aware of the dangers of cross-infection from patient to patient.

In 1959 he created an effective tranquiliser dart and rifle system. Mr Murdoch took part in testing the equipment and travelled around the world trialling it on large game animals. His equipment had variable velocity control for the syringe darts lessening the force of impact and trauma for the animal.

In 2000 Mr Murdoch was made an Officer of the New Zealand Order of Merit for his services to inventing. Last year he featured in a series of New Zealand Post stamps clever Kiwis celebrating five inventors.

Mr Murdoch was named by Time magazine as one of the 100 most influential people in the South Pacific. His inventions included improvements in electrical wiring and heat sensor devices.

In 1991 Mr Murdoch was diagnosed with cancer, a tumour that had spread from his sinuses and led to the removal of an eye, part of his jaw, and the roof of his mouth. Following his diagnosis Mr Murdoch and his wife Marilyn supported Cancer Society causes and promoted the need for people to act as early as possible with concerns about cancer. Mr Murdoch overcame this cancer, but around two and a half years ago developed oesophageal cancer. He is survived by his wife, daughter, and three sons.

This obituary was published by *The Timaru Herald* under the heading *Colin Murdoch succumbs to cancer*. We thank the editorial staff for allowing us to reprint it.

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URL: http://www.nzma.org.nz/journal/121-1279/3205/

ONZMA





Twenty years after the Cartwright Report: what have we learnt? (Conference, 28 August 2008, Auckland)

View this notice by clicking here

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Erratum

Ami Kamdar, Andrew F Muller, Stamatis Kapetanakis, Louise Thompson, David A Lythall. *A 40-year-old woman with breathlessness*. NZMJ. 2007;120(1261). http://www.nzma.org.nz/journal/120-1261/2709 and http://www.nzma.org.nz/journal/120-1261/2709/content.pdf

The NZMJ received advice saying that the surname Kapetanakis was submitted and published incorrectly as *Kapatenakis*.

Please refer to the above URLs to obtain the corrected case report.

NZMJ 25 July 2008, Vol 121 No 1278; ISSN 1175 8716 URL: http://www.nzma.org.nz/journal/121-1278/3209/