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This Issue in the Journal

Maternal and demographic factors associated with non-immunisation of Pacific infants living in New Zealand
J Paterson, T Percival, S Butler, M Williams

The Pacific Islands Families study found that 27% of mothers (n=1376) had not had their infant immunised at approximately 6 weeks of age. The factors that were associated with non-immunisation of Pacific infants were ethnic group, maternal birthplace, parity, difficulty with transport, and age of the baby at the time of the interview. These findings demonstrate the need for education about the importance of the primary immunisation series and the current schedules.

Decades of disparity: widening ethnic mortality gaps from 1980 to 1999
T Blakely, S Ajwani, B Robson, M Tobias, M Bonné

Maori and Pacific deaths have been undercounted in the mid-1980s and first half of 1990s. Correcting for this undercount, the gaps between Maori and non-Maori non-Pacific mortality widened over the 1980s and 1990s due to steadily declining non-Maori non-Pacific mortality rates and stagnant Maori mortality rates. Likewise, the gaps between Pacific and non-Maori non-Pacific mortality widened. It seems likely that the structural reforms, and the varying impact of these reforms on ethnic groups, was at least partially responsible for the widening gap.

Population need and geographical access to general practitioners in rural New Zealand
L Brabyn, R Barnett

Population based travel times to general practitioners were calculated, and this information showed how access to GPs varies across New Zealand. Travel times based on the use of private vehicles were also calculated by different population groups classified by ethnicity, age, and deprivation. The research shows that many rural regions in New Zealand have high travel times to GPs and that, in some regions, a high percentage of the population with poor access are Maori and poor. This analysis uses computer-based geographical information systems (GIS).
Maori responsiveness in health and medical research: key issues for researchers (part 1)
A Sporle, J Koea

Applications for contestable government research funding require researchers to outline how the intended research proposal contributes to Maori health. This has created difficulties for both researchers and Maori. This paper outlines nine key issues for researchers (to address in the formulation of research proposals) in the hope that this will be of assistance to both researchers and Maori.

Maori responsiveness in health and medical research: clarifying the roles of the researcher and the institution (part 2)
A Sporle, J Koea

Applications for contestable government research funding require researchers to outline how the intended research proposal contributes to Maori health. This has created difficulties for both researchers and Maori. This paper outlines the historical development of the focus on Maori research responsiveness and the legislation underpinning it. It is also argued that research institutions, rather than researchers, need to take a lead role in consulting on research issues with Maori organisations.

Clinical practice guidelines’ development and use in New Zealand: an evolving process
E McKinlay, D McLeod, A Dowell, C Marshall

Internationally, there is considerable writing about the development of evidence-based guidelines and use by clinicians. This study describes the history of guideline development in New Zealand (NZ)—and explores NZ general practitioners’ attitudes towards, and use of, guidelines. Implementation of recommendations (made as a result of this study) are reported on, and further questions about the NZ guideline movement are raised.
Immunisation and the importance of good timing

Cameron Grant

It is all about timing. Long and dedicated practice is required to achieve good timing. All athletes and performing artists know this.

The timing of our immunisation schedule is similarly based upon lessons learnt from long and dedicated research and clinical practice. In order to protect those most vulnerable to severe disease it is necessary to start immunisation at as young an age as possible. However, the capacity for the immune system to respond to an immunising stimulus is reduced in young infants. A compromise is therefore required to protect the youngest but also maintain protection through childhood and beyond. In addition, for most vaccines the immune response to a single dose is sub-optimal compared to that achieved with two or more doses.

This compromise is achieved by dividing the primary immunising dose into three—with at least 4 weeks between each dose, followed by booster doses of most of the antigens after subsequent longer intervals. Thus, in New Zealand, the primary series of diphtheria, tetanus, pertussis, polio, hepatitis B*, and *Haemophilus influenzae* type b† vaccines is delivered at ages 6 weeks, 3 months, and 5 months—with subsequent boosters in childhood and adulthood.

How important is it to start immunisation at 6 weeks of age? Can a few weeks really make such a difference? On-time delivery of the first infant vaccine doses is a keystone to successful immunisation. This is not only because young infants remain at risk of severe and sometimes fatal disease, most notably from pertussis, but also because delay in receipt of the first vaccine dose is one of the strongest and most consistent predictors of subsequent incomplete immunisation.¹,²

Research from New Zealand confirms the importance of timeliness. During the 1995 to 1997 pertussis epidemic, delay in receipt of any of the three infant doses of pertussis vaccine was associated with a four-fold increased risk of hospitalisation with pertussis.³ In the 1996 North Health regional immunisation survey, being delayed for the 6-week immunisation was associated with a 16-fold increased risk of incomplete immunisation at age 2 years.⁴

In this issue of the Journal, data is reported from the Pacific Islands Families Study on the proportion of infants whose mothers stated they had not received the 6-week immunisations, and the factors associated with non-receipt of these vaccines.⁵

This important longitudinal study has established a cohort of 1590 New Zealand-born infants of Pacific ethnic groups, 1376 (86%) of whom were visited at home at approximately 6 weeks of age. Immunisation is of particular relevance to this cohort. Pacific children experience an excessive burden from vaccine preventable disease—with hospital admission rates for measles being five times greater (and for pertussis almost two times greater) than for European children.⁶,⁷

Approximately 27% of mothers said their child had not yet received the 6 week immunisation. Data was collected for 105 (8%) of the children when they were less
than 6 weeks old, 865 (63%) when 6 to 8 weeks old, and 406 (29%) when more than 8 weeks old. Thus some were too young to have yet received the vaccines. The data presented does not enable measurement of the proportion whose immunisations were delayed. Also, verification from written immunisation records is necessary to be confident of the proportion of infants receiving all of the vaccines scheduled at age 6 weeks.

With these qualifications what do we learn from this study? First, this manuscript reminds us that a sustainable reliable method for measuring immunisation coverage in New Zealand has yet to be established. As we have had an immunisation schedule in New Zealand for over 40 years now, this is long overdue. The most reliable coverage data we have is from the 1977 Christchurch Birth Cohort Study and from the national and regional immunisation surveys performed in 1991–92 and 1996. These studies showed that, since the 1970s, between 70% and 90% of children have received the primary infant vaccine series. The immunisation surveys from the 1990s showed that between 80% and 90% of children receive the primary series, with no more than 60% of children at age 2 years having received all scheduled immunisations. There has only been a very small increase in immunisation coverage over the past 25 years. It is difficult to improve something that is not measured.

In developed countries, the three major contributors to incomplete immunisation are socioeconomic factors, healthcare factors, and parental attitudes. Healthcare factors include healthcare system barriers, provider beliefs, variability in provider practices and missed opportunities to immunise. In New Zealand, in contrast with the repeated examination of family demographics as predictors of immunisation status, examination of the health system and health professional contributions to incomplete immunisation has been less intense. Indeed, relative to the literature from other developed countries, the lack of investigation of these factors in New Zealand is notable.

Secondly, the Pacific Islands Families Study identified factors associated with non-immunisation. In addition to age and ethnic group, and after adjustment for confounding variables, children of mothers who were Pacific born, who had difficulty with transport, or who had more than five children were less likely to be immunised. The first two of these factors imply that the relationship between the family and the primary care provider contributes to incomplete immunisation. Mothers born in the Pacific may be more familiar with community-based methods of vaccine delivery (as used in several Pacific Island nations) and less aware of the need in New Zealand to find a primary care provider for their infant plus one for their own pregnancy-related health needs.

Difficulties with transport indicate an access barrier to primary care for those too poor to have a reliable vehicle. Poverty hinders immunisation not only because of its negative impact upon how the household functions but also because those who are poor do not have the same access to high-quality primary care as those who are not poor.

Given the importance of household transmission in spreading diseases such as pertussis to vulnerable infants, to be the youngest of six children, and yet be incompletely immunised, is a public health failure.
The requirements for improved immunisation coverage and timeliness have been well defined. Countries with higher immunisation rates than New Zealand have achieved this by using multifaceted immunisation strategies. Recent examples included Australia’s Seven Point Plan and the United States’ Childhood Immunization Initiative.\textsuperscript{11,12} Australia’s plan included monetary incentives for parents, incentives for general practitioners, a range of educational incentives, school entry legislation, enhanced research activity, and development of a national immunisation register.\textsuperscript{11}

A similar blueprint has already been developed for New Zealand. It was stated comprehensively by the National Health Committee in 1999.\textsuperscript{13} The key elements are national leadership and coordination of immunisation, development of a complete national immunisation information system, ensuring a stronger relationship between each child and an identified primary care provider, and greater accountability of each primary care provider for immunising all children.

Australia’s Seven Point Plan and the United States’ Childhood Immunization Initiative were introduced in response to national perceptions that the burden from immunisation preventable disease was unacceptably high. The burden from immunisation preventable disease has remained unacceptably high in New Zealand for decades—so what are we waiting for?

*For infants of hepatitis B surface antigen-positive mothers, a birth dose of this vaccine is also given.

†The primary series of \textit{Haemophilus influenzae} type b vaccine consists of two doses (given at 6 weeks and 3 months of age).

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Early diagnosis and treatment in psychotic disorders: an achievable healthcare reform strategy

Patrick McGorry

In most societies, the treatment of mental disorders and mental health problems is a low priority. Even in affluent nations, and even though they are the major cause of non-fatal disability, the coverage of these disorders by the health system is poor. Only a fraction of those with so-called high prevalence disorders, such as depression and anxiety, receive any treatment at all—while even those with lower-prevalence, more severe disorders (such as schizophrenia and bipolar disorder) typically obtain intermittent care of substandard quality, overly focused on acute episodes.

Mental healthcare is predominantly reactive, and often unnecessarily iatrogenic as a result. Stigma, prejudice, and ignorance combine to maintain a silence throughout the community, which (until recently) allowed this neglect to continue. Pervasive therapeutic nihilism, especially regarding psychotic disorders like schizophrenia, has undermined efforts to reduce the human and economic costs of these illnesses. Consequently, preventive thinking and early diagnosis has been unable to germinate or flourish in this hostile environment (until recently).

However, over the past decade, we have seen this situation begin to transform. With the advent of new treatments, new service models and increased visibility of mental health problems within the community, the early intervention paradigm has gained momentum internationally. So, for the first time, the principles of early diagnosis and phase-specific treatment have been applied to potentially serious mental disorders.

The notion—if a disease is serious and that effective treatments exist, then the diagnosis should be made at the earliest point possible—is compelling. Indeed, in cancer, heart disease, and other serious medical illnesses, it has been pursued vigorously with positive effects on morbidity and mortality. Staging is a related idea, which proposes that the specific content or mix of treatments will differ according to the stage of development of the disease, as will both the efficacy and the risks of treatment. There are many challenges raised in attempting early diagnosis, and these are made more complex in psychiatry by the lack of tests or markers of our diagnostic syndromes.

Nevertheless, the worldwide experience of this reform-process demonstrates several things. Firstly, that the available evidence supports its continued expansion. It is even proving feasible to identify and treat some patients in the pre-psychotic or prodromal phase of schizophrenia. Secondly, that it represents a realistic way forward for improved morale and workforce development—and better quality within mental health services. Treatment success, which is readily achievable at this stage, challenges therapeutic nihilism and can inspire confidence in mental healthcare, something that is in short supply as a result of the severe rationing of resources and all that flows from this. Thirdly, the success of the early psychosis paradigm may lead to a more substantial reform of healthcare—so that the major peak in incidence and prevalence in adolescence and early adulthood for a whole range of mental and
substance-use disorders can be responded to in a cohesive, logical, and acceptable manner within a youth health model. Finally, a clinical focus on onset and early course is also likely to facilitate neuroscientific advances in knowledge.

New Zealand (like Canada, the UK, and Scandinavia) has established growth points for this reform process in many centres (as a result of outstanding clinical leadership and a national commitment to better outcomes in mental health). Sustained and extended structural reform, as engineered in many places, is essential. This means a streamed system of care for young people with early psychosis—focused on detection, engagement and expert intervention during the first few years post-onset, which is known as the critical period.

However, such a stream of care must have links with yet be distinct from standard adult psychiatric services. If this does not occur, international experience shows that no sustained change in approach or quality results. Special models of primary care are also required to feed and work in synergy with such a strengthened specialist model. Ultimately, this type of reform could result in better health care for young people with any kind of potentially serious mental health problem, not only a psychosis. At the present time, it represents the best buy in mental health service development internationally.

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Maternal and demographic factors associated with non-immunisation of Pacific infants living in New Zealand

Janis Paterson, Teuila Percival, Sarnia Butler, Maynard Williams

Abstract

**Aim** To identify the proportion of infants who had not received their first dose of the primary immunisation series at approximately 6 weeks of age, and to identify the maternal and demographic factors associated with non-immunisation.

**Method** The data were gathered as part of the Pacific Islands Families (PIF): First Two Years of Life Study in which 1376 mothers were interviewed about the immunisation status of their infant. Mothers responded to questions about whether their child had been immunised, who administered the vaccines, and how satisfied they were with the care and treatment of their child in that context.

**Results** Twenty-seven percent of the mothers reported that they had not had their infant immunised at approximately six-weeks of age. Factors significantly associated (p<0.05) with non-immunisation were ethnic group, maternal birth place, parity, difficulty with transport, and age of the baby at the time of the interview.

**Conclusions** These findings demonstrate the need for education about the importance of the primary immunisation series and the current schedules, together with community resources to support mothers in the context of this infant health care initiative. Improving immunisation uptake through education may not be sufficient with the more widespread issues of deprivation and social equity needing to be addressed.

Compared with most New Zealand children, Pacific children are at increased risk of poor health with a higher incidence of respiratory infections, meningococcal disease, and infectious diseases such as measles.¹⁻³

Immunisation has been described as the first line of defence against disease, and one of the most effective health advantages available to children.⁴⁻⁵ Ensuring full and equitable distribution, accessibility, and acceptability of this health opportunity is an important health priority.⁵ The New Zealand immunisation schedule commences at 6 weeks of age and national immunisation targets have been set to achieve at least 95% coverage.⁶

Despite the demonstrated effectiveness of immunisation, current policies have become increasingly controversial due to concerns about vaccine safety. However, national and international scientific consensus is that any risks associated with immunisation are outweighed by its benefits.⁷

There are no reliable New Zealand population-derived data on immunisation rates for 6-week infants. A recent study found that 93.2% of a cohort of 979 children (registered with the childhood register in Wellington) had received their 6-week vaccines. However, this information was collected from those who remained registered with the practice and was calculated after 9 months of age.⁸
Research has shown that children who are not immunised on time are likely to be from families of low socioeconomic status, to live in urban areas, and to be members of ethnic minority groups.9,10 Other identified risk factors associated with sub-optimal uptake of immunisation include low parental educational level, inability to access appropriate transport, and single parent family.11 Also found to contribute are rising parity,12 inadequate antenatal care,13,14 negative beliefs about immunisation,9,11 and child health on the day of the appointment.9 Such risk factors suggest the need for further investigation into specific populations and the identification of barriers within subgroups.11

In view of the high rates of infectious disease and hospitalisation among Pacific infants,1–3 the Pacific Islands Families Study included questions designed to identify the proportion of infants who had not received their first dose of the primary immunisation series, as well as the maternal and demographic factors associated with non-immunisation.

**Methods**

Data were collected as part of the Pacific Islands Families: First Two Years of Life (PIF) Study. The PIF Study is a longitudinal investigation of a cohort of 1398 infants born at Middlemore Hospital, South Auckland during the year 2000.

Middlemore Hospital was chosen as the site for recruitment of the cohort as it has the largest number of Pacific births in New Zealand and is representative of the major Pacific ethnicities. All potential child participants were selected (from live births at Middlemore Hospital) if the child had at least one parent who identified as being of a Pacific Island ethnicity and who also was a New Zealand permanent resident.

Recruitment procedures occurred through the Birthing Unit in conjunction with the Pacific Islands Cultural Resource Unit that provided a daily list of Pacific admissions. Mothers were given a general description of the interview protocol, but specific areas such as immunisation were not discussed at the time of recruitment.

Approximately 6 weeks after the birth of their child, Pacific interviewers, fluent in both English and a Pacific language, visited the mothers in their homes to carry out the first interview. However, as some mothers were difficult to trace, it was not possible to administer all interviews precisely at 6 weeks.

Once eligibility criteria were established and informed consent gained, mothers participated in a 1-hour interview concerning the health and development of the child and family functioning. This interview was carried out in the preferred language of the mother. All procedures and interview protocols had ethical approval from the National Ethics Committee. Detailed information about the cohort and procedures is described elsewhere.15 Mothers responded to questions about whether their child had been immunised, who administered the vaccines, and how satisfied they were with the care and treatment of their child in that context.

Maternal and sociodemographic factors that may be associated with non-immunisation was assessed by univariate and multivariate logistic regression procedures.

**Results**

Ninety-six percent (n=1590) of potentially eligible mothers of Pacific infants (who had been born between 15 March and 17 December 2000) gave consent to be visited in their homes when the infant was 6 weeks old.

Of the 1477 mothers contacted and who met the eligibility criteria, 1376 (93.2%) agreed to participate in the study. A more conservative recruitment rate of 87.1% would include mothers who consented to contact and were confirmed eligible, or of indeterminable eligibility due to inability to trace.
Of the 1376 mothers in the cohort (1.7% gave birth to twins), 47.2% self identified their major ethnic group as Samoan, 21% as Tongan, 16.9% as Cook Islands Maori, 4.3% as Niuean, 3.4% as Other Pacific, and 7.2% as Non-Pacific.

The Other Pacific group includes mothers identifying equally with Pacific and Non-Pacific groups, or with Pacific groups other than Samoan, Tongan, Cook Island Maori, or Niuean. The Non-Pacific group refers to mothers of infants fathered by Pacific men. The mean (SD) age of mothers was 27 (6.2) years, 80.5% were married or in de facto partnerships, 33% of mothers were New Zealand-born, and 27.4% had post-school qualification.

Approximately 73% of the mothers reported that they had immunised their infant. The majority of these mothers (97.1%) reported that they were satisfied with the care provided by their doctor. The main problems that were cited by mothers were being unhappy with the treatment, or having difficulties associated with communicating with the doctor.

Table 1 lists the variables examined for potential association with non-immunisation of infants in the cohort. For the categories within each variable, the numbers and percentages of mothers who did not have their infant immunised are given, along with the associated odds ratios. Mothers who were under 20 years of age, with post-school qualifications, and those who described themselves as fluent in English were significantly less likely to have had their infant immunised at 6 weeks of age.

Strong cultural alignment with the Pacific, but not New Zealand, way of life and customs, and difficulties with transport were also significantly (p<0.05) associated with non-immunisation. With regard to specific ethnicity, Samoan mothers were significantly more likely to report that they had immunised their infant. The age of the infant at the time of the interview was also significantly associated with non-immunisation. Those infants who were older than 8 weeks were significantly more likely to have been immunised than younger infants.

Maternal birthplace, household income, attendance at antenatal classes, parity, social marital status and number of years lived in New Zealand did not reach significance.
Table 1. Numbers (row percentages) and univariate odds ratios for non-immunisation of 6-week infants by selected variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Immunisation status</th>
<th>Univariate odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>(%)</td>
</tr>
<tr>
<td>Infant age</td>
<td>&lt;6 weeks</td>
<td>18</td>
<td>(17.1)</td>
</tr>
<tr>
<td></td>
<td>6-8 weeks</td>
<td>627</td>
<td>(72.5)</td>
</tr>
<tr>
<td></td>
<td>&gt; 8 weeks</td>
<td>363</td>
<td>(89.4)</td>
</tr>
<tr>
<td>Maternal age (yrs)</td>
<td>&lt;20</td>
<td>70</td>
<td>(63.1)</td>
</tr>
<tr>
<td></td>
<td>20-29</td>
<td>531</td>
<td>(73.8)</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
<td>376</td>
<td>(75.2)</td>
</tr>
<tr>
<td></td>
<td>40+</td>
<td>31</td>
<td>(70.5)</td>
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<tr>
<td>Ethnicity</td>
<td>Samoan</td>
<td>518</td>
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<tr>
<td></td>
<td>Cook Island Maori</td>
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<tr>
<td></td>
<td>Niuean</td>
<td>40</td>
<td>(67.8)</td>
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<td></td>
<td>Tongan</td>
<td>203</td>
<td>(70.2)</td>
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<tr>
<td></td>
<td>Other Pacific</td>
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<td>(46.8)</td>
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<td></td>
<td>Non Pacific</td>
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<td>(70.7)</td>
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<td>Social marital status</td>
<td>Partnered</td>
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<td>Non partnered</td>
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<td>Education</td>
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<td>(73.9)</td>
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<td>Years lived in NZ</td>
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<td>(78.0)</td>
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<td>6-10</td>
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<td>(71.4)</td>
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<td>&gt; 10</td>
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<td>(72.2)</td>
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<td>Characteristic</td>
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<td>--------------------------------------</td>
<td>---------</td>
<td>--------------</td>
<td>--------</td>
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<td>English fluency</td>
<td>Yes</td>
<td>604 (71.0)</td>
<td>247 (29.0)</td>
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<td>No</td>
<td>404 (77.0)</td>
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<td>307 (70.4)</td>
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<td>89 (19.9)</td>
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<td>2-4</td>
<td>571 (74.3)</td>
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<td>5+</td>
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<td>103 (62.0)</td>
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<td>135 (29.5)</td>
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<td>$20,001-$40,000</td>
<td>526 (74.1)</td>
<td>184 (25.9)</td>
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<td></td>
<td>&gt;$40,001</td>
<td>126 (78.3)</td>
<td>35 (21.7)</td>
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<td></td>
<td>Unknown</td>
<td>34 (70.8)</td>
<td>14 (29.2)</td>
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<td>Attended antenatal classes</td>
<td>Yes</td>
<td>87 (77.0)</td>
<td>26 (23.0)</td>
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<tr>
<td></td>
<td>No</td>
<td>916 (73.0)</td>
<td>338 (27.0)</td>
</tr>
</tbody>
</table>

* P<0.05; † P<0.01; ‡ P<0.001

Includes mothers identifying equally with two or more Pacific Island groups, equally with Pacific Island and non Pacific Island groups, or with Pacific Island groups other than Tongan, Samoan, Cook Island Maori or Niuean.

Cultural alignment is measured by the General Ethnicity Questionnaire and assesses high and/or low alignment with Pacific and/or mainstream New Zealand way of life and customs.
When controlling for the effects of all Table 1 variables in a multiple regression model, factors that were significantly associated (p<0.05) with non-immunisation were ethnic group, maternal birth place, parity, difficulty with transport, and age of the baby at the time of the interview.

**Discussion**

The finding that over a quarter of mothers (26.7%) had not had their child immunised at approximately 6 weeks of age demonstrates the need for education about the importance of immunisation and schedules, together with community resources to support mothers in the context of this infant healthcare initiative.

When controlling for a range of potentially confounding variables, including the age of the child at the time of the interview, those mothers who were less likely to have their child immunised with the first dose of the primary immunisation series were: Pacific born, had more than 5 children, and had difficulty with transport.

Pacific-born mothers may have less knowledge about immunisation schedules, which is likely to impact on their decision as to whether to have their child immunised in infancy. These findings also suggest that those mothers with a large number of children and those who had limited access to transport may find it difficult to get to their GP or clinic. It appears that improving immunisation coverage through education may not be sufficient and that the more widespread issues of deprivation and social equity need to be addressed. In terms of ethnicity, Tongan, Cook Islands Maori, Niuean, Other Pacific, and Non-Pacific mothers were significantly less likely than Samoan mothers to have had their child immunised.

The age of the infant when the interview was conducted was significantly associated with non-immunisation, with those infants older than 8 weeks more likely to have been immunised. Thus, if all interviews had been carried out at 8 weeks, then the proportion of infants who had received their first immunisation dose is likely to be higher.

We did not look at factors that may be associated with a delay in immunisation. One factor that has been highlighted in previous research is that Pacific parents are more than twice as likely to believe that immunisations are too upsetting and painful for very young children.

Information and reassurance (pertinent to specific problems that parents are experiencing) are thought to have maximum effect on parental commitment to immunisation. Studies have shown that some children are not appropriately immunised because their mothers are not given satisfactory information. Furthermore, many parents lack first-hand experience with diseases, and may underestimate their communicability and potential harm.

Findings from qualitative investigations have highlighted to the problems associated with long waiting times, lack of discussion time with the doctor, crowded clinics, and the bringing and minding of other children.

It has been suggested that opportunistic immunisation by doctors, flexible immunisation provision, and government incentives may be the key to higher immunisation levels. Accurate, accessible and current records, and effective tracking systems would further facilitate a clear understanding of immunisation status, and
help identify children who are at high risk. It is equally important that interventions provide ongoing supportive environments (to facilitate access to immunisation services for mothers at each point in the immunisation process).

There are several limitations that need to be considered. Firstly, the study does not provide a comparative group of non-Pacific infants. Secondly, it was the intention of the study to collect data at 6 weeks; however, due to difficulties tracking some families, all infants were not reached precisely at that time. Our data shows that those infants visited later were more likely to have been immunised, thus it is possible that the infants visited earlier (at 6 weeks), who were not immunised, may have received their vaccinations in the following months.

However, the Pacific Islands Families Study does begin to provide data in this area of recognised public health importance where, despite being a Child Health priority, robust contemporary data are lacking. Furthermore, longitudinal analysis at 12 and 24 months will build a clearer picture of immunisation patterns among Pacific children living in New Zealand.

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References


Decades of disparity: widening ethnic mortality gaps from 1980 to 1999

Tony Blakely, Shilpi Ajwani, Bridget Robson, Martin Tobias, Martin Bonné

Abstract

Background Maori and Pacific deaths were severely undercounted in the mid-1980s and first half of 1990s, resulting in numerator-denominator bias when calculating mortality rates by ethnicity. We used the New Zealand Census-Mortality Study to adjust for this bias and calculate corrected ethnic-specific mortality rates from 1980 to 1999.

Methods Age-specific adjusters were calculated for the period 1980–99. They were applied to mortality data to obtain a corrected number of deaths. Mortality rates (by age and gender) were calculated by dividing the total number of adjusted deaths by the respective census counts.

Results Contrary to unadjusted rates, corrected Maori and Pacific mortality rates were clearly higher than non-Maori non-Pacific rates during the 1980s and early 1990s. From 1980–84 (1361 per 100,000 for males and 965 per 100,000 for females) to 1996–99 (1258 and 894), there was only a modest decrease in Maori 1 to 74 year old mortality rates. Pacific mortality rates changed little from 1980–84 (1264 and 672) to 1996–99 (1144 and 696 per 100,000 for males and females respectively). Non-Maori non-Pacific mortality rates, however, decreased by about 30% from 1980–84 (919 and 553) to 1996–99 (641 and 407 per 100,000 for males and females, respectively).

Cancer (lung, prostate, breast, colorectal) mortality rates tended to increase over time among Maori compared to steadily decreasing among non-Maori non-Pacific. Of note, Pacific colorectal cancer mortality rates have increased by about ten-fold during the 1980s and 1990s. All ethnic groups experienced falls in cardiovascular disease mortality rates, but the decreases were much greater among non-Maori non-Pacific.

Conclusion The gaps between Maori and non-Maori non-Pacific mortality widened over the 1980s and 1990s mainly due to steadily declining non-Maori non-Pacific mortality rates and stagnant Maori mortality rates. Likewise, the gaps between Pacific and non-Maori non-Pacific mortality also widened during that period.

This paper presents Maori, Pacific, and non-Maori non-Pacific mortality rate trends during the 1980s and 1990s. The results presented in this paper, for the first time, correct for ‘undercounting of Maori and Pacific deaths’ and ‘modest overcounting of non-Maori non-Pacific deaths’ that occurred during that period. This so-called numerator-denominator bias for ethnicity recording between census and mortality data has been known about for some time. However, it is only with the recent record linkage of census and mortality data in the New Zealand Census-Mortality Study (NZCMS) that we can now accurately determine ethnic mortality trends.
comparison of the self-identified ethnicity of an individual at the previous census and the ethnicity on the death registration form. Consequently, it was possible to ‘unlock’ the numerator-denominator bias and calculate age-specific adjustment ratios (adjusters) to correct the discrepancy in the ‘numerator’.

The results in this paper are the culmination of a substantial body of work that has been published previously in this journal\textsuperscript{7–9} and in reports published elsewhere.\textsuperscript{10–12}

Accurate ethnic mortality trend data is essential for the Government to monitor trends on population health outcomes. Socioeconomic and ethnic inequalities in mortality represent a category of health outcome of particular concern.\textsuperscript{13} It is of particular interest to monitor what happened to ethnic mortality trends during the 1980 to 1999 period, a period of major structural change in the New Zealand economy and society overall.

**Methods**

**Mortality data**—Mortality data was provided by the New Zealand Health Information Services (NZHIS) for the years 1980–1999 (by year of registration of death). Years were grouped into four periods: 1980–84, 1985–89, 1990–1995, and 1996–99. Note that the third period is of 6 years’ duration, and the fourth period of four years’ duration. This variation was due to a major change in the collection of mortality data ethnicity in late 1995. Up until then, only Maori or Pacific ethnicity was allowed on mortality data, and all remaining deaths (without the Maori or Pacific options identified) were assigned as non-Maori non-Pacific. During the late 1990s, the ethnicity question was changed to be consistent with the 1996 census, and was made compulsory.

**Census data**—For each of the four above periods, 1981, 1986, 1991, and 1996 census data (by strata of sex, age, and ethnicity) was used as denominator data in the calculation of mortality rates. This paper predominantly reports the prioritised ethnic series whereby ethnicity was assigned as Maori if one of the three possible self-identified ethnicity responses on the 1986 or the 1991 or the 1996 census was Maori.

Therefore, for Maori, the prioritised ethnic group represents the total Maori Ethnic Group (MEG). For those not allocated as Maori, the prioritised ethnic group was assigned as Pacific if one of the self-identified ethnic groups was Pacific. The remaining records were assigned as non-Maori non-Pacific. The 1981 census collected degree of ethnic origin. To form a prioritised series for the 1981 census, we assigned as Maori those who recorded any degree of Maori ethnic origin. Of the remainder, those who recorded any degree of Pacific ethnic origin were categorised as Pacific. Although the definition is not identical to the 1986 and 1991 censuses, it is similar enough to form a time series.

We also determined mortality rates for a sole series—although not the major focus of this paper. Here, census respondents were assigned as sole Maori or sole Pacific if only one ethnicity was identified.

**Calculating adjustment ratios for numerator-denominator bias**—The quantification of numerator-denominator bias, and consequent adjustment ratios, have been presented in detail elsewhere.\textsuperscript{9,11,12} Briefly, we cross-classified census prioritised ethnicity counts by mortality data ethnicity counts (prioritised for 1996–99; the single [and only] option for three earlier periods) for decedents aged 1–74 years in each 3-year period after the censuses during the 1980s and 1990s. (The NZCMS is not well-suited for calculating ratios for infant deaths and deaths aged 75 years and older.)

From these cross-classifications, we calculated census to mortality ratios (adjusters) for Maori, Pacific, and non-Maori non-Pacific. There was marked variation in these ratios by age, with greater bias in younger age groups. Therefore, age-specific adjusters were used to recalculate mortality rates. A ratio greater than 1.0 for Maori, for example, corresponds to more Maori being on census data compared to mortality data (ie, mortality data undercounting Maori relative to census data).

Finally, we smoothed the observed ratios across 5-year age categories for analyses in this paper (see pages 59–61 and Table 2 of reference 12 for details on smoothing and actual ratios used).

**Calculating age-standardised mortality rates**—The observed number of deaths in each sex by age by ethnicity (by cause of death) strata (according to NZHIS data) was multiplied by the above adjustment ratios. These corrected mortality counts and the census (prioritised) counts were then used to calculate
Results

Figure 1 shows the age-standardised 1-74 year old mortality rates for the prioritised ethnic series—both unadjusted and adjusted for numerator-denominator. Without using adjustment ratios, Pacific mortality rates up to the mid-1990s appear to be lower than both Maori and non-Maori non-Pacific mortality, and there appears to be little difference between Maori and non-Maori non-Pacific mortality.

In the late 1990s, due to much-improved recording of ethnicity on mortality data, the unadjusted mortality rates jump markedly for Maori and Pacific. This unadjusted pattern is clearly spurious. Had we used sole census data for denominators in the first three periods, the unadjusted Maori and Pacific mortality rates would have been somewhat higher—but still underestimated.

Figure 1b and Figure 1d show the male and female corrected age-standardised mortality rates (actual rates are in Table 1). First, among non-Maori non-Pacific, there has been a 30% and 26% reduction in mortality rates over the 20-year period for males and females, respectively. In contrast, there was only a modest decrease in Maori mortality rates (8% for males and 7% for females), and no obvious change in Pacific mortality rates. Second, these divergent mortality trends by ethnicity meant that the gaps between Maori and non-Maori non-Pacific, and between Pacific and non-Maori non-Pacific, widened over the 1980s and 1990s.

The rate ratio comparing Maori to non-Maori non-Pacific increased from 1.48 in 1980–84 to 1.96 in 1996–99 for males, and from 1.74 to 2.20 for females. The rate ratio comparing Pacific to non-Maori non-Pacific increased from 1.38 in 1980–84 to 1.79 in 1996–99 for males and from 1.22 to 1.71 for females. Third, and not shown in Figure 1 and Table 1, Maori and Pacific mortality rates using a sole definition of ethnicity tended to be higher again. Additionally, whereas the prioritised series shown in Figure 1 may be consistent with a small decrease in Maori mortality rates from 1980–84 to 1996–99, the sole series demonstrated no change. (Full information on the sole series is presented elsewhere.)

The above patterns of strong improvements in non-Maori non-Pacific mortality rates, and little (if any) improvement in Maori and Pacific mortality rates were similar across age groups—except, perhaps, among Pacific children (1–14 year olds) and youth (15–24 year olds), and Maori 25–44 year olds where reductions have occurred (Figure 2 and Table 1).

Nevertheless, the mortality gaps between Maori and non-Maori non-Pacific among 25–44, 45–64 and 65–74 year olds were large (especially the 45–64 year olds) and widening over time.
Table 1. Age-standardised all-cause mortality rates (per 100,000; 95% confidence intervals in parentheses) by ethnicity (prioritised series) by age group and sex

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<tr>
<td>1-14 years</td>
<td>Maori</td>
<td>49.0 (44.8-53.2)</td>
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<td>41.8 (38.2-45.3)</td>
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<td>159 (150-169)</td>
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<td>103 (99.5-106)</td>
<td>106 (102-109)</td>
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<td>72 (68.9-75.9)</td>
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<td>25-44 years</td>
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<td>277 (264-290)</td>
<td>262 (252-273)</td>
<td>253 (242-264)</td>
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<td>Pacific</td>
<td>199 (177-220)</td>
<td>212 (193-231)</td>
<td>180 (166-193)</td>
<td>213 (196-230)</td>
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<tr>
<td></td>
<td>non-M non-P</td>
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<td>123 (120-126)</td>
<td>113 (111-116)</td>
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<td>45-64 years</td>
<td>Maori</td>
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<td>1734 (1685-1783)</td>
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<td>1310 (1204-1415)</td>
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<td>65-74 years</td>
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<td>5469 (5291-5647)</td>
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<td>Pacific</td>
<td>4567 (4078-5057)</td>
<td>5075 (4653-5496)</td>
<td>4185 (3922-4448)</td>
<td>4421 (4148-4695)</td>
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<td>non-M non-P</td>
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<td>2592 (2569-2615)</td>
<td>2122 (2098-2147)</td>
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<td>1-74 years</td>
<td>Maori</td>
<td>1361 (1323-1399)</td>
<td>1265 (1232-1298)</td>
<td>1296 (1266-1326)</td>
<td>1258 (1227-1289)</td>
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<td>1264 (1143-1384)</td>
<td>1155 (1083-1227)</td>
<td>1122 (1065-1178)</td>
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<td>non-M non-P</td>
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<td>850 (844-855)</td>
<td>745 (740-749)</td>
<td>641 (636-646)</td>
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**Females**

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<td>1-14 years</td>
<td>Maori</td>
<td>55.4 (49.1-61.6)</td>
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<td>15-24 years</td>
<td>Maori</td>
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<td>227 (211-243)</td>
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<td>169 (137-201)</td>
<td>209 (178-239)</td>
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<td>non-M non-P</td>
<td>145 (140-151)</td>
<td>156 (150-162)</td>
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<td>102 (96.1-108)</td>
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<td>25-44 years</td>
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<td>356 (335-377)</td>
<td>328 (311-344)</td>
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<td>254 (220-288)</td>
<td>271 (241-301)</td>
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<td>45-64 years</td>
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<td>2070 (1988-2152)</td>
<td>2012 (1936-2087)</td>
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<td>1631 (1462-1799)</td>
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<td>65-74 years</td>
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<td>6543 (6255-6830)</td>
<td>6146 (5865-6428)</td>
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<td>Maori</td>
<td>965 (935-995)</td>
<td>886 (860-911)</td>
<td>927 (905-950)</td>
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<td>Pacific</td>
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<td>525 (521-528)</td>
<td>461 (458-464)</td>
<td>407 (404-410)</td>
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non-M: non-Maori; non-P: non-Pacific.
Table 2. Age-standardised mortality rates (per 100,000; 95% CIs in parentheses) by ethnicity (prioritised series) for causes of death and age-groups shown in Figure 3, Figure 4 and Figure 5

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<td>Lung Ca</td>
<td>Maori</td>
<td>84.2</td>
<td>(76.0-92.3)</td>
<td>76.3</td>
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<td>(42.5-68.5)</td>
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<td>(8.3-14.7)</td>
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<td>(11.7-29.8)</td>
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<td>non-M non-P</td>
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<td>(8.2-9.3)</td>
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<td>Colorectal Ca</td>
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<td>(9.8-16.1)</td>
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<td>(4.9-17.2)</td>
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<td>IHD</td>
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<td>(147-151)</td>
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<td>(45.5-58.2)</td>
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<tr>
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<tr>
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<td>IHD</td>
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IHD: Ischaemic heart disease; Ca: Cancer; non-M: non-Maori; non-P: non-Pacific; Unintent: Unintentional.
Figure 1. Age-standardised all-cause mortality rates (per 100,000) by ethnicity (prioritised series), by sex for 1-74 year olds, and unadjusted and adjusted for numerator-denominator bias
Figure 2. Age-standardised all-cause mortality rates (per 100,000) by ethnicity (prioritised series) by age for 1–74 year olds (sexes combined)
Figure 3: Age-standardised lung-, prostate-, breast-, and colorectal-cancer mortality rates (per 100,000) by ethnicity for 1–74 year olds

Column legend as in Figure 2: Maori first column (black background, white spots); Pacific second column (white background, black spots); non-Maori non-Pacific third column (white background, black diagonal stripes). Error bars are 95% confidence intervals.
Figure 4. Age-standardised ischaemic heart disease (IHD), stroke, and respiratory mortality rates (per 100,000) by ethnicity for 1–74 year olds

Column legend as in Figure 2: Maori first column (black background, white spots); Pacific second column (white background, black spots); non-Maori non-Pacific third column (white background, black diagonal stripes). Error bars are 95% confidence intervals.
Figure 5. Age-standardised 1-74 year olds unintentional injury and 15-24 and 25-44 year old suicide mortality rates (per 100,000) by ethnicity

Column legend as in Figure 2: Maori first column (black background, white spots); Pacific second column (white background, black spots); non-Maori non-Pacific third column (white background, black diagonal stripes). Error bars are 95% confidence intervals.
The mortality trends varied markedly by cause of death as shown in Figure 3, Figure 4, and Figure 5 for the prioritised series (data in Table 2). (Patterns were similar using the sole series.) There was a strong pattern of diverging Maori and non-Maori non-Pacific lung cancer mortality rates, such that (by 1996–99) the relative risks were 3.50 (males) and 4.91 (females). Pacific lung cancer rates were similar to those for non-Maori non-Pacific females, but intermediate for males. Prostate cancer mortality rates increased over time among Maori, while remaining essentially stable among non-Maori non-Pacific.

By 1996–99 non-Maori non-Pacific prostate cancer rates were half those of Maori. Pacific prostate cancer rates appeared to decrease over time. Breast cancer mortality rates increased among both Maori and Pacific females, compared to decreases among non-Maori non-Pacific females. By 1996–99, non-Maori non-Pacific breast cancer mortality rates were 60% of those for Maori.

Pacific breast cancer mortality rates appear to have become the highest of all three ethnic groups in the 20-year period (although 95% confidence intervals include the Maori female rate). At the beginning of the 20-year period, Pacific breast cancer mortality rates were clearly the lowest of the three ethnic groups. In the early 1980s, Maori had colorectal cancer mortality rates one-third (females) to two-thirds (males) of those for non-Maori non-Pacific people.

In contrast to increasing rates among Maori, minor decreases in age-standardised mortality rates among non-Maori non-Pacific people over the last 20 years, have resulted in similar colorectal cancer mortality rates by the late 1990s. While rates are imprecise for Pacific people, it appears that there has been an even more substantial increase in colorectal cancer mortality among this group. At the end of the 20-year period, all three ethnic groups have roughly comparable colorectal cancer rates.

Ischaemic heart disease mortality rates tended to decrease over time for all ethnic groups and both sexes—although not much for Maori and Pacific males, thus resulting in widening gaps. Stroke mortality rates were clearly highest for Pacific people among males and (possibly) females. All ethnic groups had decreasing stroke mortality rates over time. Respiratory disease mortality decreased for all three ethnic groups. However, there were always large excesses of Maori male and female respiratory mortality compared to non-Maori non-Pacific people, and likewise for Pacific males (Figure 4).

Unintentional injury mortality rates decreased over time for all ethnic groups and both sexes. This pattern was similar for road traffic crashes—a major contributor to unintentional injuries (not shown here). Suicide rates increased most notably among both Maori males and females over the 1980s and 1990s. Increasing suicide mortality for Pacific and non-Maori non-Pacific males was also evident—but the increases were not as marked as for Maori (Figure 5).

**Discussion**

This paper presents mortality rates by ethnicity for the 1980s and 1990s. Most importantly, the underlying mortality data have been corrected for numerator—
denominator bias for the first time in New Zealand. There are clear and concerning patterns.

Most notably, there has been little (if any) decline in Maori and Pacific mortality rates over these two decades (1980s and 1990s) despite a steady decline in non-Maori non-Pacific mortality. As a consequence of this divergent pattern by ethnicity in mortality trends, the inequalities between Maori and Pacific and non-Maori non-Pacific mortality have markedly increased over the last two decades.

By cause of death, decreasing mortality rates (for cardiovascular disease, respiratory disease, and unintentional injury) among Maori and Pacific people have been off-set by increasing cancer (both lung cancer and non-tobacco related cancers) and suicide mortality rates. Further, even for those diseases with decreasing rates over time among all ethnic groups (eg, ischaemic heart disease), the relative inequalities between ethnic groups have tended to increase over time.

Whilst these results are more accurate than previous official mortality statistics by ethnicity for the 1980s and 1990s, there are still two important limitations. First, our adjustment for numerator–denominator bias is unlikely to be exactly correct. We were only able to use approximately two-thirds of the eligible mortality records to calculate the adjustment factors. However, extensive sensitivity analyses lead us to conclude that the results are accurate. 

Second, the best we could do was to adjust ethnicity recording on mortality data to the self-identified ethnicity on the corresponding census.

The concept and recording of census ethnicity has varied for each of the 1981, 1986, 1991, and 1996 censuses. This instability of ethnic classifications is a major problem for the 1991 to 1996 census comparisons for Maori. That said, any change in the ethnic group composition over time is at the margin and will not alter the major finding of diverging ethnic mortality trends.

Why are we observing these diverging ethnic mortality trends? We believe this question requires attention from a range of researchers and analysts. For the purposes of this paper, we will outline three (not mutually exclusive) types of explanation: epidemiological, structural, and health services.

Epidemiologically, these patterns appear most consistent with period effects rather than age or cohort effects. The colorectal cancer trends among Pacific people are particularly notable, and presumably reflect the lag-time from exposure to Western lifestyles commencing in the late 1950s and 1960s following migration to New Zealand.

Lung cancer rates increased among both Maori and Pacific people (particularly females) during the 1980s and 1990s (in contrast to decreases among non-Maori non-Pacific males and a possible peaking of mortality in the early 1990s for non-Maori non-Pacific females). As the cause of death most strongly associated with tobacco, these mortality trends obviously reflect tobacco consumption trends by ethnicity that occurred a decade or so prior to the death event.

Regarding cancer generally, incidence rates overall are somewhat similar between ethnic groups for non-lung cancer, yet there are marked mortality differences.
Development of cancer control strategies in New Zealand must address the contribution of cancer to increasing ethnic mortality gaps. Projecting out 5 to 10 years based on the cardiovascular mortality trends in this paper, premature heart disease death is going to be uncommon among non-Maori non-Pacific. Consequently, health promotion programmes and treatment services to reduce heart disease need to increasingly focus on addressing Maori and Pacific populations.

Much of the disparities in mortality between ethnic groups are likely to be due to parallel disparities in classic risk factors for poor health such as tobacco. However, there is wide acceptance that socioeconomic factors are underlying determinants of health, either by the way socioeconomic position determines risk factor exposures or by other mechanisms such as health services access.

Access to income, education, and other resources influences one's health by a myriad of pathways including behaviour, health services, and psychosocial mechanisms. Between 1980 and 1999, New Zealand underwent major social and economic changes including a substantially flattened tax system; fully targeted income support; a regressive consumption tax (GST); market rentals for housing; privatised major utilities; user-charges for health, education, and other government services; and a restructured labour market designed to facilitate ‘flexibility’.

These social and macroeconomic changes did not impact equally on Maori and non-Maori. Indeed, inequalities between Maori and non-Maori widened in employment status, education, income, and housing—key social determinants of health.

Specifically, unemployment rates for Maori rose from levels similar to non-Maori in the early 1980s to three times that of non-Maori in the late 1980s. Furthermore, real incomes of Maori households dropped during this period and did not recover to the level they were at in the early 1980s.

The stasis in Maori mortality rates presented in this paper for the 1980s and 1990s was preceded by marked improvements in life expectancy in the 1950s to 1970s. Major structural change in the New Zealand economy and society, therefore, seemed to coincide with no further improvement in Maori health.

We do not contend that structural change is the full or only explanation for diverging ethnic mortality trends during the 1980s and 1990s. For example, many chronic diseases take years or decades to manifest, meaning that deaths during the 1980s and 1990s would have causal antecedents both during this period and prior. However, it is also very clear from ex-Soviet countries that sudden increases in mortality can rapidly follow social upheaval and change.

Therefore, we argue that structural change in New Zealand was a major contributor to the diverging ethnic mortality trends reported in this paper. Indeed, a prediction by Maori leaders at Hui Taumata in 1984 that the structural reform policies would make Maori the ‘shock absorbers in the economy’ seems to have materialised in health (and other social) statistics.

Health services are not responsible for all, or even the majority, of socioeconomic and ethnic inequalities in health; however, they undoubtedly play a role. For example, US research found that co-payments discouraged visits for low-income people, irrespective of how medically necessary the visit was thought to be (including visits for preventive care). There is evidence that cost barriers are also an issue in New
Zealand. An iwi general practice in Taranaki found the introduction of an $8.00 part charge for community cardholders led to a dramatic decrease in attendance (30%) among a group with extremely high health needs, and the co-payment was subsequently dropped.\textsuperscript{32}

Recent surveys in New Zealand have found that adults with below-average income were more likely to report having gone without needed care because of the cost.\textsuperscript{33,34} The Commonwealth Fund 2001 Survey also found that Maori adults were twice as likely as Pakeha to have gone without needed care in the past year because of the cost—partly reflecting income differences. However, even when controlling for income, access concerns were significantly higher for Maori.\textsuperscript{35}

A significant body of research examining ethnic health disparities in the United States has found that white Americans receive a higher quality of health services, and are more likely to receive even routine medical procedures than other ethnic groups. These differences were found to be associated with greater mortality among African-American patients.\textsuperscript{35}

The ratio of Maori to non-Maori mortality for all adult cancer is higher than the same ratio for disease incidence.\textsuperscript{15} This pattern is indicative of higher case fatality rates among Maori compared to non-Maori once they have cancer, suggesting an important role for health services to reduce ethnic inequalities. Despite higher mortality from cardiovascular disease, there is evidence that Maori and Pacific people receive fewer cardiac interventions than would be expected.\textsuperscript{36} Westbrooke et al (2001) found that these differences remained even after controlling for sex, age, and deprivation (NZDep96).\textsuperscript{37}

Where to from here? There is clearly a need for further investigation, analysis, and understanding of the concerning trends in inequality shown in this paper. For example, the contribution of trends in a range of socioeconomic factors to trends in mortality by ethnicity needs more thorough analysis than that offered by considering just one socioeconomic factor or one point in time.\textsuperscript{8,38} Likewise, the contribution of health services and epidemiological risk factors needs further investigation. Such improved understanding should then translate into action to reduce ethnic inequalities in health.

**Statistics New Zealand security statement**

The New Zealand Census Mortality Study (NZCMS) is a study of the relationship between socioeconomic factors and mortality in New Zealand, based on the integration of anonymised population census data from Statistics New Zealand and mortality data from the New Zealand Health Information Service. The project was approved by Statistics New Zealand as a Data Laboratory project under the Microdata Access Protocols in 1997. The data sets created by the integration process are covered by the Statistics Act and can be used for statistical purposes only. Only approved researchers who have signed Statistics New Zealand's declaration of secrecy can access the integrated data in the Data Laboratory. (A full security statement is in a technical report at [http://www.wnmeds.ac.nz/nzcms-info.htm](http://www.wnmeds.ac.nz/nzcms-info.htm) For further information about confidentiality matters in regard to this study, please contact Statistics New Zealand.
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We also thank the many researchers and analysts who have commented on the work presented in this paper—including Cindy Kiro, Papaarangi Reid, and Andrew Sporle; many staff members of Te Kete Hauora and the Ministry of Health; staff of the Ministry of Social Development; and colleagues at the Wellington School of Medicine and Health Sciences.

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References:


Population need and geographical access to general practitioners in rural New Zealand

Lars Brabyn, Ross Barnett

Abstract

Aims To use a geographical information system (GIS) approach to demonstrate the extent to which different areas in New Zealand vary in their geographical access to GPs, and to analyse the extent to which spatial access varies in relation to different population groups.

Methods Three methods; population/GP ratios, least cost path analysis (LCPA), and an allocation method (which considered the capacity constraint of GPs) were used to demonstrate differences in geographic accessibility to GPs. Travel time, and distance to the closest GP, was calculated for every census enumeration district in New Zealand (n=38336)—thus enabling population-based accessibility statistics to be calculated and aggregated to the territorial local authority level. These calculations include the average travel time if everybody visited a GP once and the population more than 30 minutes from a GP. The composition of this population is analysed according to three criteria of need: the level of deprivation (NZDep2001), ethnicity (% Maori), and age (% <5 years, and % 65 years and over).

Results There are significant regional variations in geographical accessibility in New Zealand, and these differences are dependent upon the method to calculate accessibility. Ratio measures give a different picture of GP access than the other two indicators, reflecting the fact that TAs with similar ratios often have wide variations in travel times as well as the size and proportion of the population living more than 30 minutes from the closest GP. TAs with larger numbers and a higher proportion of their populations living in such areas tend to be more deprived and have a higher proportion of Maori, especially in the North Island. There appears to be no significant trend by age.

Conclusion Given the health and service consequences of poor access, the results suggest that more attention needs to be paid to extending the spatial information base in primary care, in order to achieve more effective planning of services for disadvantaged populations.

Accessible and appropriate health services for people living in rural areas remains an issue of ongoing concern. The implementation of the Primary Health Care Strategy, together with the more recent development of primary health organisations (PHOs), both build on earlier government policies designed to improve the level and continuity of service provision in rural areas.1-2 While such developments provide an opportunity to improve the effectiveness and sustainability of rural primary health care services, a number of important questions remain. These include problems of funding rural care, difficulties in attracting GPs and other health professionals to isolated rural areas, problems of high doctor turnover and continuity of care, as well as the influence of...
geographical and financial barriers, which may serve to limit the utilisation of needed services.\textsuperscript{3,4}

New Zealand, with its rugged physical environment and dispersed rural population, poses particular problems for the location and use of services. An important requirement, therefore, is to develop quality information systems that highlight the physical accessibility of primary care, and the extent to which this access varies for particular rural population groups.\textsuperscript{5}

Improving the quality of information on accessibility to rural primary health care is also an important requirement for effective decision-making by PHOs and District Health Boards (DHBs). The objective of this paper, therefore, is two-fold:

- To use a geographical information system (GIS) approach to demonstrate the extent to which different areas in New Zealand vary in their geographical access to GPs, and
- To analyse the extent to which spatial access varies on the part of different population groups.

The Rural Expert Advisory Group’s report, *Implementing the Primary Health Care Strategy in Rural New Zealand. A Report from the Rural Expert Advisory Group to the Ministry of Health*, has indicated that high levels of deprivation are a feature of some rural regions in New Zealand, and that the extra travel costs that rural people incur make access to primary health care services particularly difficult for the people of these communities.\textsuperscript{6}

Therefore, an important task is to identify those areas where problems of physical accessibility to GPs are compounded by increased needs for care and conditions of rural disadvantage.

**Methods**

A geographical information system (GIS) was used to measure geographical (physical) accessibility to GPs. Three key methods were compared. First, population/GP ratios were calculated for each of the 73 Territorial Local Authority areas in New Zealand (using full-time equivalent GP data for the year 2000 provided by the Ministry of Health and population data from the 2001 Census).

Second, since population/GP ratios are only a crude measure of geographical access, two further methods were used: least cost path analysis (LCPA) and an allocation technique that considers the number of GPs available and how many people a GP can service. Both methods represent an improvement on traditional ratio measures of GP access, as they involve more detailed calculations of travel distances and travel times. In addition, they are not constrained by area boundaries and aggregation problems of ignoring the intra-district location of GPs relative to their patients.

LCPA involved calculating a least cost path algorithm to determine the shortest travel distance and time between each of the 38,336 census meshblocks (origin nodes) in New Zealand, as well as the closest GP practice (destination nodes). Network analysis capabilities in ARC/INFO were used to calculate accessibility. The *nodedistance* command computes distances between all possible combinations of origin and destination nodes via the New Zealand road network.

In this study, nodes closest to the meshblock centroids were the origin nodes and nodes closest to GP practices (n=1390 practices representing 3614 GPs) were the destination nodes.

To identify the closest GP for a given Census centroid, we calculated the minimum distance for each origin to each destination. The minimum distance to the closest GP for each centroid was the sum of three calculations: the network distance, plus that from the meshblock centroid and GP surgery to their closest road nodes, respectively.
The process for calculating the minimum travel time to the closest GP is similar, except road travel time is used instead of distance. Estimated road travel times were based on whether the road was inside or outside an urban area, number of lanes, condition of the road surface (sealed versus unsealed), and the bendiness (sinuosity). The road travel times, while similar to those published by the New Zealand Automobile Association, do not take account of the effects of travel congestion or seasonal differences. Full details of their derivation and limitations are given in Brabyn and Gower.  

Since the population characteristics of each Census meshblock are known, it was also possible to calculate average travel times. This was accomplished by multiplying the population of each centroid by the travel time of the centroid (to determine the total time spent travelling if everyone represented by the centroid visited the closest GP once). To calculate the total travel time, these values were then aggregated to the level of the TA. The average travel time was obtained by dividing this total by the TA population.

While LCPA approaches represent an improvement on ratio methods of determining geographic access to GPs, they can be misleading because not all patients choose to use the closest GP. LCPA, therefore, provides estimates of optimum rather than actual travel distances and times. Furthermore, it ignores the fact that some GPs have multiple practices, especially in rural areas where these may also be partly staffed by other health professionals for part of the time. LCPA also neglects the capacity of a GP practice to service the surrounding population.

Many people may be unable to get an appointment because the GP is servicing a large population and hence may choose another provider, especially in more densely populated areas where other alternatives are available. Despite this caveat, an allocation method was also used to estimate variations in GP access. This involved allocating potential patients to the closest GP practice until the practice reaches a specified capacity level. The model then finds the next closest GP practice. Once a population has been allocated a GP, the network travel time and distance is calculated.

The capacity used in this study was 1400 patients per full-time GP—which is the number used by the Ministry of Health for a full-time workload. The output from the allocation method is similar to LCPA except for the addition of a capacity constraint. However, the allocation method is also limited because of its assumption of a uniform capacity constraint, which clearly varies between GPs especially depending upon their gender and age.

Both the LCPA and allocation analyses enabled estimates of the total population with poor geographic access to GPs to be calculated. For the purposes of this analysis, a 30-minute threshold was chosen. Thirty minutes is a long time to travel to a GP and, given the results of US research, most persons would have expressed dissatisfaction at having to travel for this length of time.

The three methods are first compared, followed by the analysis of the population composition of rural areas remote from GPs. Four measures of population need are considered: the 2001 New Zealand Deprivation Index (NZDep2001), the proportion of the population of Maori ethnicity, and two indicators of age (percentage less than 5 years old, and the percentage aged 65 years and over). These measures enable the assessment of population groups that are particularly vulnerable to poor geographical access.

The method outlined above contains generalisations that can skew the results but are necessary for practical reasons. First, meshblocks are represented by one central point, and the location of this point may not accurately depict the population distribution within the meshblock (which will be a problem with large rural meshblocks found in the South Island). There is a new data set being developed in New Zealand (called LandOnLine) that contains address points, which will map the location of every letterbox in the country. This data set has been completed for many TAs and can be used to represent the population distribution within a meshblock.

Preliminary analysis using the geographical mean of the address points within a meshblock shows that travel times are 2–3% less than with meshblock centroids. Therefore, the method used for this study overestimates travel times for rural areas. The second generalisation used by the method is that it only considers travel speeds during normal flow and does not consider traffic congestion that is happening in urban centres during rush hour traffic.

A temporal dimension to accessibility would be a worthwhile research endeavour if data on travel speeds at different times of the day were known.
Results

Comparison of the three techniques as indicators of GP access—Figure 1 shows the population/GP ratios by TA, while Figures 2 and 3 show the population more than 30 minutes from a GP using the LCPA and allocation models.

Figure 1: Population (by territorial authority) per GP
Figure 2: Population (by territorial authority) more than 30 minutes from a GP; using LCPA (least cost path algorithm)
There are many other statistics that can be generated from the LCPA and allocation models (including the average travel time, total travel time, and travel distance); however, these statistics can be misleading as the average travel time does not consider the population affected by this time.
Furthermore, a region may have a high average travel time but only have a low population. For example, Westland District has a high average travel time (20.8 minutes—based on the allocation model) but only has a population of 8,091.

It would therefore be inappropriate for the Government to use only average travel time as a basis for funding. It is possible to present the total travel time for each district and use this for a comparison. However, this statistic is high for populated cities because of the large populations even though the average travel times are less than three minutes. The population more than 30 minutes from a GP is therefore the preferred statistic to use when representing geographical access.

The results generated from the LCPA and allocation models can be represented at a range of scales from individual meshblock units to national statistics. The average travel time to the GP for the whole of New Zealand is 4.6 and 5.9 minutes for the LCPA and allocation models respectively.

The population more than 30 minutes from a GP for the whole of New Zealand is 70,833 and 122,034 for the LCPA and allocation models, respectively. To compare regional variations in accessibility across New Zealand, it is necessary to choose a scale where the number of regions is manageable, and where the regions are not too large so that important variations within a unit are generalised.

Figures 1, 2, and 3 were compiled according to territorial authority (TA) regions, which is a good compromise. District Health Board regions could also be used but these cover large areas and there are significant variations within them as shown by the territorial authority scale.

A visual comparison of the models (Figures 1–3) shows that they all provide a different representation of access. Specifically, there is weak correlation between ‘population per GP’ and the LCPA and allocation models (0.14 and 0.17, respectively). However, this is to be expected given that they are completely different methods for measuring accessibility.

Population per GP does not consider the distribution of the population or the GPs within a particular TA whereas the LCPA and allocation models are not constrained by area boundaries in the same way that the population per GP method is. Rather, times from GP locations to the closest population enumeration point are calculated. The effect of this difference can be seen in the comparative results for Waikato District. Using the population per GP method, Waikato District has the highest ratio (2343 people per GP). However using LCPA and calculating population (more than 30 minutes travel time from a GP), the district is mid range in its accessibility (33 out of 73).

This disparity is because many of the GPs that service the Waikato District are located in the city of Hamilton and towns of Cambridge and Morrinsville, which are all within 8 km of the Waikato District boundary. Waikato District is predominantly a rural district that is serviced by Hamilton City, which has its own TA status. This detail is neglected in the ratio method.

There is a strong correlation between the LCPA and allocation models (0.88), which is expected since the methods are similar. Where there is a significant variation between these models, then this indicates that functional access is a problem.
Selwyn District and Waikato District have substantial differences between these models (3432 and 3303 people respectively) and there are 17 TAs with differences between the models of over 1000 people. All these TAs can be characterised as rural. Virtually all the major urban TAs have no difference between the LCPA and allocation models. As expected, the population more than 30 minutes from a GP using the allocation model is either equal or more than the LCPA model.

The LCPA and allocation models use travel time that only includes actually time spent travelling by car and not time spent loading the car and finding a park. The travel time in cities appears very low but the travel distance is on average less than one kilometre. It needs to be emphasised that this analysis is intended to produce general statistics rather than assessment of individual travel times.

LCPA and allocation models produce results that clearly differentiate between urban and rural districts. Urban territorial authorities have low travel times, as there tends to be many GP services within a sort distance. Conversely, high travel times in rural districts describe the dispersed characteristics of populations and concentrated GP locations in provincial towns.

Variations between rural districts reflect differences in population distribution, which in turn is related to land-use, livelihood, and topography. For example, the Far North District is long and narrow with a large population living outside of service towns. Conversely, the Waikato District has a high rural population but also a high number of service towns.

**GP access by population group**—While rural regions are more likely to have problems of access to key services, an important question is the extent to which problems of GP access vary between TAs depending upon their population characteristics. LCPA and allocation models combined with the NZ Deprivation Index (a score of 10 is the most deprived) and census data has been used to produce a range of statistics for different ethnic, age, and deprivation groups—and this was completed for each TA and DHB.

This produces large tables that are not possible to present in a journal publication. Table 1 was generated from the allocation model and provides a sample of this data. It includes the Far North District and Southland District, which have the highest population that is more than 30 minutes from a GP. They are also geographically separated as they are at opposite ends of the country. For comparison, Table 1 also shows two urban TAs (Waitakere City (which is part of Auckland), and Christchurch City) and statistics for the whole of NZ. The average travel time for the different population groups is also presented.

At a national level, there are variations in geographical access for the different population groups; however these do not appear to be significant (this is statistically demonstrated in Table 2, which is discussed later).

If people are split into two groups—wealthy (NZ Dep 1-3) and poor (NZ Dep 8-10)—then it can be said that wealthy people generally have higher travel times to GPs (as many wealthy people purchase lifestyle blocks on the outskirts of cities, and due to the existence the wealthy farming communities.
Table 1. Accessibility to GPs by different population groups

<table>
<thead>
<tr>
<th>POPULATION GROUP</th>
<th>NZ Av* Time (min)</th>
<th>NZ</th>
<th>NZ %</th>
<th>CHRIST-CHURCH</th>
<th>CHRIST-CHURCH %</th>
<th>WAITAKERE</th>
<th>WAITAKERE %</th>
<th>FAR NORTH</th>
<th>FAR NORTH %</th>
<th>SOUTH-LAND</th>
<th>SOUTH-LAND %</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALL</td>
<td>5.9</td>
<td>128034</td>
<td>3.4</td>
<td>0</td>
<td>0.0</td>
<td>243</td>
<td>0.1</td>
<td>9357</td>
<td>17.0</td>
<td>6624</td>
<td>22.8</td>
</tr>
<tr>
<td>UNDER 5</td>
<td>6.0</td>
<td>9336</td>
<td>3.5</td>
<td>0</td>
<td>0.0</td>
<td>12</td>
<td>0.1</td>
<td>720</td>
<td>17.2</td>
<td>450</td>
<td>23.1</td>
</tr>
<tr>
<td>OVER 65</td>
<td>4.7</td>
<td>10119</td>
<td>2.2</td>
<td>0</td>
<td>0.0</td>
<td>39</td>
<td>0.3</td>
<td>1002</td>
<td>14.7</td>
<td>444</td>
<td>14.4</td>
</tr>
<tr>
<td>MAORI</td>
<td>6.7</td>
<td>23118</td>
<td>4.4</td>
<td>0</td>
<td>0.0</td>
<td>30</td>
<td>0.1</td>
<td>4350</td>
<td>20.0</td>
<td>504</td>
<td>21.1</td>
</tr>
<tr>
<td>PACIFIC IS.</td>
<td>3.4</td>
<td>1233</td>
<td>0.5</td>
<td>0</td>
<td>0.0</td>
<td>6</td>
<td>0.0</td>
<td>222</td>
<td>16.8</td>
<td>21</td>
<td>18.4</td>
</tr>
<tr>
<td>REST</td>
<td>5.9</td>
<td>103683</td>
<td>3.5</td>
<td>0</td>
<td>0.0</td>
<td>207</td>
<td>0.2</td>
<td>4785</td>
<td>14.9</td>
<td>6099</td>
<td>23.0</td>
</tr>
<tr>
<td>NZ Dep 1</td>
<td>5.9</td>
<td>7971</td>
<td>2.1</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>1500</td>
<td>27.8</td>
</tr>
<tr>
<td>NZ Dep 2</td>
<td>7.0</td>
<td>14352</td>
<td>3.8</td>
<td>0</td>
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<td>0</td>
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<td>0.0</td>
<td>2037</td>
<td>28.4</td>
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<tr>
<td>NZ Dep 3</td>
<td>6.6</td>
<td>13635</td>
<td>3.6</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>768</td>
<td>24.5</td>
</tr>
<tr>
<td>NZ Dep 4</td>
<td>6.9</td>
<td>17784</td>
<td>4.8</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>267</td>
<td>6.0</td>
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<tr>
<td>NZ Dep 5</td>
<td>6.1</td>
<td>16044</td>
<td>4.3</td>
<td>0</td>
<td>0.0</td>
<td>108</td>
<td>0.7</td>
<td>0</td>
<td>0.0</td>
<td>252</td>
<td>9.7</td>
</tr>
<tr>
<td>NZ Dep 6</td>
<td>5.7</td>
<td>14601</td>
<td>3.9</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>156</td>
<td>4.1</td>
<td>357</td>
<td>22.6</td>
</tr>
<tr>
<td>NZ Dep 7</td>
<td>5.2</td>
<td>13344</td>
<td>3.6</td>
<td>0</td>
<td>0.0</td>
<td>135</td>
<td>0.6</td>
<td>807</td>
<td>13.2</td>
<td>327</td>
<td>22.9</td>
</tr>
<tr>
<td>NZ Dep 8</td>
<td>4.4</td>
<td>7800</td>
<td>2.1</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>1107</td>
<td>15.4</td>
<td>363</td>
<td>21.4</td>
</tr>
<tr>
<td>NZ Dep 9</td>
<td>4.2</td>
<td>8520</td>
<td>2.3</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>1872</td>
<td>19.1</td>
<td>528</td>
<td>38.4</td>
</tr>
<tr>
<td>NZ Dep 10</td>
<td>5.5</td>
<td>13392</td>
<td>3.6</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>5415</td>
<td>27.7</td>
<td>192</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Average
Elderly people generally spend less time travelling to their GP and this can be explained by the deliberate move many retired people make to be closer to health services. The under 5 years group appear to be close to the average. Maori people have higher travel times, on average, which can be explained by the rural nature of many Maori communities. As for Pacific Islanders, they have less travel time (on average), and this can be explained by the large, urban Pacific Island population in Auckland.

When different TAs are studied, there can be significant variations to these trends. It is clear from Table 1, that there is no significant problem with geographical access for any of the population groups in the two urban TAs, both in terms of the absolute number of people and as percentages. This is the case with all the urban TAs. In the Far North District, there is a complete reversal of the national trend in terms of wealthy and poor people, although the absolute population of wealthy people is low (2454). However, Southland District supports the national trend.

Table 2 illustrates correlations between three measures of GP access and the socioeconomic characteristics of all TAs, and also provides a separate analysis of the North and South Islands. Regarding average travel times to GPs, it is clear that rural areas with lower population densities have poorer accessibility, as do areas with larger Maori populations, especially in the North Island.

By contrast, TAs with the highest concentrations of more affluent groups (deprivation deciles 1-3), in general, had shorter travel distances to care than was true for more deprived populations (deciles 8-10). TAs with concentrations of older people (65 years and over) also had smaller average travel times to GPs, but only in the South Island.

These patterns are also evident with respect to the two other access measures (the % total population more than 30 minutes from a GP based on LCPA and allocation methods). However, here the correlations are magnified between poor access and levels of deprivation and ethnicity, especially in the North Island. In contrast to the travel time analysis, in both cases, the relationship between (poor) levels of geographical access and deprivation is strong ($r=-0.57$ and $-0.55$) for the LCPA and allocation measures, respectively.

These patterns are illustrated in Figures 2 and 3, which show the absolute population more than 30 minutes from a GP in different TAs and compare the LCPA and allocation techniques. The pattern is a predictable one. Many of the traditional Maori heartlands, such as Gisborne or the Far North, have larger populations with poorer access, but so do many of the more remote southern TAs such as Southland or Marlborough.

For New Zealand as a whole, the LCPA analysis indicates that 70,833 people (or 1.9%) resided more than 30 minutes from their closest GP. This figure rises to 128,034 (or 3.4%) when the results of the allocation analysis are examined. While the latter figure may not seem particularly high (3.4%), the proportion of the population with poor access rises to 9.9% for all rural TAs (those outside the main metropolitan areas and regional cities), and exceeds this margin for over half (24) of the 45 more rural TAs.
Table 2. Correlations between GP access and population characteristics of TAs

<table>
<thead>
<tr>
<th></th>
<th>New Zealand</th>
<th>North Island</th>
<th>South Island</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average Travel Time</td>
<td>LCPA30&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Alloc30&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>% Low Dep (Deciles 1-3)</td>
<td>-0.17</td>
<td>-0.35</td>
<td>-0.23</td>
</tr>
<tr>
<td>% High Dep (Deciles 8-10)</td>
<td>-0.03</td>
<td>0.14</td>
<td>0.03</td>
</tr>
<tr>
<td>% Maori</td>
<td>0.17</td>
<td>0.32</td>
<td>0.19</td>
</tr>
<tr>
<td>% Young</td>
<td>-0.09</td>
<td>-0.05</td>
<td>-0.07</td>
</tr>
<tr>
<td>% Old</td>
<td>-0.06</td>
<td>-0.10</td>
<td>-0.07</td>
</tr>
<tr>
<td>Urban&lt;sup&gt;3&lt;/sup&gt;</td>
<td>-0.66</td>
<td>-0.46</td>
<td>-0.57</td>
</tr>
<tr>
<td>Population density</td>
<td>-0.52</td>
<td>-0.34</td>
<td>-0.42</td>
</tr>
</tbody>
</table>

<sup>1</sup>Population more than 30 minutes from GP based on LCPA as % total TA population;

<sup>2</sup>Population more than 30 minutes from GP based on allocation analysis as % total TA population;

<sup>3</sup>Binary variable where 1 = TA contains regional city or metropolitan area, 0 = Otherwise
Discussion

The results presented here suggest that problems of GP access remain important for many of the more remote rural areas in New Zealand. Many people in these areas suffer a double burden. Not only do they face long travel times for obtaining primary care, but also since they are often deprived, travel difficulties are accentuated.

Other research has indicated that the economic costs of obtaining care represent a significant deterrent to low income people in New Zealand. Malcolm, for instance, in a survey of eight health centres providing services to Maori and low-income New Zealanders, found that rates of GP utilisation were substantially lower (from 37 to 74%) than the national average of 4.5 visits per capita in 1994/95. But, given that the centres were set up to improve access to Maori and low-income populations, and had significantly reduced the financial barriers present in the average general practice, then cost barriers alone did not appear to be a major factor for the very low rates of utilisation observed; the effects of geographical and cultural barriers were just as important.

Although the present study did not examine GP utilisation rates in areas remote from GPs, Malcolm’s results are consistent with a large, and longstanding, geographic literature demonstrating links between geographic barriers and utilisation rates (both for primary and hospital care). For instance, Haynes and Bentham found that GP consultation rates, outpatient attendance rates, and inpatient admissions in Norfolk (UK) were all found to decline with decreasing accessibility.

The groups most affected in rural areas were those with the highest relative need for healthcare. Other research has similarly found that distance barriers disproportionately affect poorer patients. For higher-status patients, distance barriers will have less effect on utilisation not only because of greater levels of affluence and car ownership, but also because of a preference to take advantage of non-local providers of both primary and hospital care.

However, as Girt and others have found, distance may have both a positive and negative effect on consulting behaviour. Individuals are likely to become more sensitive to the development of disease the further they live from a doctor, but (at the same time) distance negatively affects their propensity to consult. The distance at which this effect changes seems to depend upon the extent of the self-perceived illness or condition.

The effect of ‘distance to GP’ on ‘rates of use’ also has implications for the use of hospital services. In rural New South Wales, Walmsley found that the chances of admission diminished the further a patient lived from hospital. Haynes et al similarly found that (after controlling for needs and provision) distance to hospital produced a 17–37% reduction for different types of admissions.

Of particular importance was their finding that distance to GP surgeries had the effect of reducing hospital inpatient episodes—an effect which was greatest for elective and psychiatric admissions.

These findings suggest that ‘distance’ and ‘travel time’ are important considerations, especially for rural dwellers (who frequently express the greatest dissatisfaction with problems of access to care). An accumulated body of research thus suggests that
policymakers should give greater weight to such parameters when evaluating the availability and quality of primary care in rural areas.

Traditionally, analyses of future directions in primary healthcare have either neglected the importance of spatial analysis approaches or, where analyses have taken place, they have been on the basis of crude GP population ratios. However, such an approach, on its own, is an insufficient basis for assessing the effects of poor access and planning future needs.

Population-based ‘travel time’ and ‘distances to health services’, as well as an analysis of the characteristics of the population most affected by geographic barriers are more useful measures of GP accessibility—and we suggest that future primary healthcare policy should pay more attention to such factors. Such considerations will become more important as PHOs take on the task of identifying and addressing those groups in their populations that have poor health or are missing out on services.

The application of GIS approaches, such as those discussed in this paper and which are beginning to be widely used in health research, therefore provide a valuable tool for assisting such organisations in improving access to services and the health of the most disadvantaged. The use of GIS tools, however, requires access to quality data. One of the most time consuming challenges of this research was obtaining a geographically referenced database of GP practices.

Currently the GP register maintained by the NZ Medical Council does not contain reliable information on the geographical location of GP practices. An address of each practice is kept, but this could be the GP’s residential address. The addresses of GP practices were obtained from a commercial data supplier, whose usual clients would likely be pharmaceutical companies. The conversion of addresses to a GIS layer is labour intensive and should only be done once.

Lastly, it is imperative that the Ministry of Health or the New Zealand Medical Council maintains a geographically referenced data set that contains New Zealand grid reference coordinates of GP practices, along with the number of GPs working in the practice and the hours they work.

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**References**


Maori responsiveness in health and medical research: key issues for researchers (part 1)

Andrew Sporle, Jonathan Koea

Abstract

Introduction Application for contestable government-research funding and ethical approval requires researchers to outline how their intended research project contributes to Maori development or advancement.

Methods and Results When formulating their research proposals, the key issues for researchers are research utility, defining Maori, informed consent, confidentiality, issues with human tissues and genetic material, participant remuneration and recognition (koha), intellectual property, and involvement of local Maori health or social services.

Conclusions The most common Maori responsiveness issues in research applications can be readily approached by researchers who address straightforward methodological concerns, by working through precedents established by peers and colleagues, as well as by working with end-users of their research.

In 1998, the Health Research Council of New Zealand (HRC) published the Guidelines for researchers on health research involving Maori. These Guidelines were produced by the Maori Health Committee of the HRC to assist health researchers intending to undertake research that involved Maori as participants, or was on a topic relevant to Maori health.

The HRC guidelines were not binding on researchers but were more than ‘points to consider’ as they were to be used in the consideration of applications for HRC funding in future years. The 1998 revision of the ‘National application form for ethical approval’ incorporated the principles contained within the HRC guidelines. As a result, all applicants from all research fields were required to indicate if they had read the guidelines and to specify what consultation with Maori had been undertaken in developing the research. The current HRC research proposal application form requires the host institution to ensure that consultation with Maori has occurred.

Anecdotal reports and the authors’ personal experiences indicate that this requirement for all researchers has led to confusion among researchers and ethics committees as to what constitutes appropriate and meaningful consultation with Maori. This is confirmed by a study on researchers’ views of the functioning of ethics committee in New Zealand. There is also anecdotal evidence that the requirement for consultation by researchers is placing demands on Maori communities or organisations with limited resources and their own, more pressing, matters to attend to.

This paper attempts to clarify the issues regarding consultation with Maori in the development of biomedical and clinical research. Our experience (in assisting health researchers improve the Maori responsiveness of their intended projects) has
highlighted that there are nine key areas that researchers can readily address in their proposals.

These issues are outlined in this paper, together with possible strategies to manage them. The paper concludes with a review of the first year of functioning of the Maori Research Review Committee of the Auckland District Health Board—an initial institutional committee formed to address these issues. A second paper\(^3\) will review the historical development of the Maori responsiveness requirement for health research funding to demonstrate that this process follows similar requirements of the rest of the health sector, and will outline an institutionally based model to assist researchers in meeting the obligations related to Maori responsiveness.

**Common issues of Maori responsiveness in research applications**

In their roles (within research-funding bodies, universities, and healthcare providers) the authors have provided advice to biomedical, clinical, and public health researchers on ways of improving the Maori responsiveness of their intended research projects. Over the last 5 years, nine issues have predominated in such discussions with researchers. All of these issues are readily addressed, as outlined below.

**Utility**

Whenever possible, health research on a health issue relevant to Maori should have clear benefits for Maori health. Such benefits need to be clearly articulated, and the research process must be designed to realise those benefits.

Research undertaken in New Zealand can often overlook its relevance for Maori health, and this may significantly undervalue the research project. The first step is for the researcher to recognise the relative impact of the health issue being researched upon different population groups—including Maori. This should include an assessment of likely future relevance given the marked changes in New Zealand’s population over the next 50 years.

For public health and clinical research, this assessment of relative impact on population groups is usually straightforward (as the burden of most health issues falls disproportionately upon Maori). Occasionally, the ethnic specific burden of a health issue may not be known, but addressing this gap in knowledge can then be an additional research outcome.

For example, the initial planning of an investigation into possible causes of abdominal aortic aneurysm in New Zealand had not included consideration of ethnicity. However, a detailed examination (of ethnic specific incidence and mortality) highlighted a previously unknown higher mortality and earlier incidence of aortic aneurysm in Maori.\(^4\) This was a key research finding, as it was the first time such elevated rates have been described outside a population of non-European descent, and the results are now being used to inform further research into potential modifiable causes of aneurysm for Maori.

The second step is to ensure that the benefits of the research reflect the relative impact of the health issue. A vital part of this process is the identification of, and consultation with, potential end-users of the research results. Both HRC and the Foundation for Research, Science and Technology (FRST) applications require researchers to
indicate the relevance of their project, the relationship with endusers and the strategy for the dissemination of results.

Addressing Maori responsiveness requires a similar process, but made Maori-specific. Where a research team has a focus on a specific issue, the consultation with Maori or non-Maori endusers is likely to involve an ongoing reciprocal relationship that may shape the research focus, design, and methods—or the dissemination strategy across the team’s research portfolio. Suitable Maori end-users may be any combination of Maori staff or sections within mainstream organisations working with Maori on the health issue, or Maori-specific health or other community organisations.

One strategy is to include a specific focus on Maori within the project. This may involve undertaking ethnic-specific analyses, or ensuring there are sufficient Maori participants to enable Maori specific analyses. Some projects include a distinct Maori segment, involving Maori specific research processes and Maori staff.

With clinical studies, the combination of small participant numbers and sampling strategy can preclude a distinct ethnic analysis, especially when the research is exploratory in nature. In such instances, the researcher should specify in their application the anticipated proportion of the sample that will be Maori (based on previous clinical activities) and determine whether this enables a statistically valid ethnic specific analysis. If not, then the option of an ethnic over-sampling should be explored, and the decision regarding its practicability justified within the application.

Where ethnic-specific analyses are not possible, then the research and dissemination process can be designed to enable the research to form the basis of later work that is more directly relevant to Maori health.

Some researchers have chosen to exclude Maori as subjects from studies due to investigator-perceived difficulties in consultation, recruitment, or analysis. This is an effective means to ensuring that the Crown-funded research has an unknown applicability to Maori. Of note, the United States’ National Institutes of Health (NIH) insists that women and minorities be included in all NIH biomedical and behavioural research involving human participants—to ensure that the results are applicable to all population groups. Furthermore, where there is prior evidence of differential clinical or public health importance of the health issue, then both ‘the primary question(s) to be addressed by the proposed … trial and the design of that trial must specifically accommodate this.’

Subgroup analyses are required where the evidence of differential impact is equivocal and strongly encouraged, even when there is no prior evidence of differential impact. Exceptions are possible, but only when ‘a clear and compelling rationale and justification establishes to the satisfaction of the relevant Institute/Center Director that inclusion is inappropriate.’ New Zealand’s research and health policies would suggest a similar requirement could be made for Crown-funded research in this country.

For biomedical research, the benefits for Maori health may not be so readily identifiable—as the research is concerned with more fundamental biological processes, many steps removed from application in a health setting. However, there may still be ways the research could contribute to Maori health development—these need to be explored and practicable options (if any) outlined in the research proposal.
In such instances, the research process may be able to provide workforce development opportunities via studentships or scholarships that can assist in addressing the low levels of Maori participation in biomedical research. Another option is for biomedical researchers to focus on an issue of high Maori health relevance.

In 1964, a paper was published that described a Maori family in which members had died of diffuse gastric carcinoma. However, this Maori family did not benefit from this research in terms of improved surveillance or treatment. Nearly 30 years later, a joint venture between the family and biomedical researchers at Otago University resulted in definition of an inherited genetic defect in cell adhesion proteins integral to the development of diffuse gastric cancer. This partnership led to an innovative research process that has resulted in major publications, development of local community health services, further research projects and the establishment of improved surveillance and treatment protocols for family members.

The Royal Society of New Zealand has recently published a report outlining good practice guidelines for working with Maori in scientific research.

**Defining and identifying Maori**

Undertaking ethnic specific analyses can be a useful way of highlighting differences in morbidity and mortality between population groups as well as highlighting differences in effectiveness of services or other interventions. All of these analyses can be useful in informing improvements in health policies and practices for Maori. To make this possible, research projects need to use standardised definitions and processes for determining the ethnic identity of participants.

The use of non-standardised definitions and processes makes the results non-comparable with other studies (or even official data), and introduces bias that reduces the usefulness of the results in informing improvements in Maori health. Although this problem has plagued official health statistics in the past, it does not need to affect current or future research.

The solution is to use the content, delivery, and counting methods of ethnicity questions contained in the most recent New Zealand Census. The use of the standard Census question ensures that the results are comparable with the Census data (that forms the baseline population data for the determination of incidence or prevalence rates).

As ethnicity is a self-defined concept, and the Census is (usually) self-completed, researchers should get participants to answer the question (if possible). The researcher then needs to use the standard means of aggregating the results (especially multi-ethnic responses) into ethnic categories. Finally, it is also important for authors to describe the methods used when writing up the project.

In 2001, Thomas reviewed research reports, which made comparisons between Maori and non-Maori samples from 1980 to 1996. Only 19% reported any information on the criteria used for categorising ethnicity, and only three papers mentioned how people of dual or multiple ethnicity were defined. As with other research methods, outlining ethnicity criteria and their application in publications is essential for the audience to assess the validity and applicability of the research results.
Informed consent

Obtaining informed consent for involvement as a participant in a research process usually involves the consent of the individual concerned, or (in certain circumstances) proxy consent from parents, family, guardians, or persons with power of attorney.

However, for Maori, a more collective approach to consent may be required depending on the nature of the research processes involved. This is especially true when the research process involves traditional Maori knowledge or processes that challenge Maori values or tikanga.

For Maori, traditional knowledge is entrusted to individuals. As such, it is not universally available despite it remaining the property of the collective and cannot be shared with the consent of the collective stakeholders. With the exception of genealogical information and traditional therapies, most mainstream health research will not involve such information. When traditional knowledge or potential breaches of tikanga (Maori lore and protocol) are involved in research processes, then individual consent is insufficient. For traditional knowledge, the consent of the collective (whanau [family], hapu [subtribe], or iwi [tribe]) is required.

Where issues of tikanga are involved, then the HRC guidelines require that the mana whenua (people with authority) of the region (such as the local iwi) need to be consulted, and the results of the consultation documented in the application. In addition, it is prudent for researchers to provide opportunity (including the necessary time) during the consent process for potential Maori participants to discuss their involvement with whanau.

Confidentiality

Participation in research usually involves confidentiality of participant identity. Maintaining this confidentiality can be difficult for Maori, especially with smaller or regional studies. The combination of extensive Maori social networks and (possibly) small numbers of eligible Maori participants requires researchers to minimise the inclusion of identifiable information in any research reports or publications—to avoid the unintentional identification or mis-identification of an individual, community, or organisation.

Conversely, Maori participants may ask that their research information is made available beyond themselves (in line with collective accountability, or to ensure wider benefit from the research process for their communities). The research application should specifically indicate if either of these situations could apply to the intended project, and (if so) they should include a strategy to address the issue.

Handling and disposal of tissue

Maori view all tissue and body fluids as taonga (to be treated as a treasure). However, body fluids and tissues are also regarded as tapu (and therefore need to be treated with caution) rather than noa (neutral). This distinction is important, since biological specimens must be treated with great care and kept away from food and cooking utensils.

The process of consent to the taking of tissue and body fluids (as part of a research protocol) amounts to entrusting the researcher with this taonga. Consent for tissue or
body fluid collection is not given lightly, and consequently all tissues should be handled with respect. Many universities and hospitals already have protocols for the sampling, storage, and disposal of tissue from Maori. These can include Maori supervision of the process, and rituals for the cleansing of the storage site or samples. Where samples are required, it is important that the researcher seek and follow the advice of the local Maori advisory or management team and document this in their application.

It is expected that where tissues and body fluids will be transported (particularly outside of New Zealand), there will be evidence of specific processes in place to ensure that samples are used only for the purposes for which consent has been provided and then disposed of in a suitable manner. The application form should outline what protocols are being followed for handling human tissue and what, if any, specific processes are being followed for any Maori specimens.

**Genetic information**

The use of genetic material from Maori, as well as from indigenous flora and fauna, is highly contentious and there is a general reluctance amongst Maori to be involved in genetic research. Many of these contentious issues have been discussed by Baird et al., or are outlined in the submissions to the Royal Commission on Genetic Modification. However, several Maori-specific genetic projects have proceeded, including at least two researcher-initiated projects. In all cases, extensive consultation was required with whanau, hapu, and iwi. Involving Maori in mainstream projects is less straightforward. Possible strategies include excluding Maori from such a study or not collecting ethnicity data, making Maori samples non-identifiable. Again, researchers should familiarise themselves with the issues, then follow local protocols in determining how to address this issue and refer to these in their applications.

**Intellectual property**

Intellectual property issues are an important consideration for researchers, particularly those involved in the development of patentable knowledge or new services.

If a research project involves a unique contribution from Maori organisations or individuals, then that contribution needs to be given due recognition in the research process. Important issues for Maori are retaining control over things that are viewed as being owned by them, and the prevention of exploitation. Researchers must remember that ownership of Maori knowledge is often collective, and that intellectual property rights need to be negotiated with organisations or kin groups (whanau, hapu, or iwi) rather than individuals. Previous mechanisms to acknowledge intellectual property within the research process have included authorship (primary and joint) on publications as well as joint ownership of intellectual property.

In the case of Guilford et al the intellectual property relating to discovery of the e-cadherin gene in gastric cancer is jointly owned by both whanau and the institution hosting the research. This is clearly defined in a contract between the researchers’ host institution and the whanau trust.
If this issue is relevant to an application, then the applicant should either include a description of how any intellectual property would be managed, or outline the process that will resolve how the issue will be managed.

**Koha**

It may be appropriate to provide koha (a gift) to participants in recognition of the contribution that participants make to the research process. The recent Operational Standard for Ethics Committees 16 allows for reimbursement for participation, including any costs incurred by the participant. Such reimbursement needs to be reasonable, and indicated in advance to potential participants.

Financial incentives to participate can negate the basis of informed consent as well as create a source of bias in recruiting a research sample, and should therefore be discouraged. However, it may be appropriate to provide participants with a small gift in recognition of their time and contribution. Often this will be in the form of a letter or certificate of thanks/acknowledgement. Other possible examples are petrol or book vouchers, or gifts of food. One way to ensure that a koha is not regarded as an inducement is not to signal it in advance to participants.

In projects where reimbursement or koha may be provided, researchers should include (within their applications) a description of any reimbursement and or koha, clearly outlining the amount or form of the koha and whether potential participants are advised in advance.

**Involvement of regional Maori health services**

Most biomedical centres in New Zealand have now established Maori health services within the District Health Boards (DHB), which work to assist Maori undergoing medical treatment—either by advocacy, or by more practical assistance such as accommodation and transport.

In the case of clinical research, discussion of the intended research protocol with the regional Maori Health services is one important avenue of consultation. In addition, Maori Health services are often able to assist with patient recruitment, interaction between researchers and primary healthcare providers, and dissemination of results.

Any such involvement should always be negotiated during the development of a research proposal—to ensure the Maori health service staff workload is not compromised, and to ensure any required costs are built into the research budget.

Inclusion of a regional Maori Health Services’ contact phone number on patient information sheets for clinical research protocols also allows Maori Health Services to assist researchers in supporting Maori patients and their whanau through the research process.

**The Maori Research Review Committee of the Auckland District Health Board**

At the Auckland District Health Board (ADHB), a Maori Research Review Committee has been developed. The Committee meets once a month to review Treaty of Waitangi and tikanga aspects of all research to be carried out within Auckland District Health Board institutions.
The Committee was formed by Maori working within the ADHB in response to issues that have been outlined in this paper. Prior to its formation, most research proposals were being directed informally toward Maori working in the organisation for review—this was an unsatisfactory arrangement for both researchers and Maori.

All research applications are now directed through the District Health Board Research and Development Office, and are reviewed by the Maori Research Review Committee. This committee includes a Maori clinician, a Maori nurse, a representative from the Research Development Office (who provides secretarial and administrative support), representatives from the local ethics committee, and mana whenua.

All research is assessed in terms of adherence to the guidelines prepared by the Committee to assist researchers. Research that deals with difficult or contentious areas will be directed to a group of Maori kaumatua/leaders (the kaunihera) who regularly advise the ADHB on all aspects of their work.

The Committee does not rewrite the Treaty components of a submission but simply indicates whether the research meets the institutional guidelines in this area or points out deficiencies and makes suggestions regarding improvement. Furthermore, the Committee strives to be constructive and to help researchers develop research proposals that are relevant to Maori, and to answer questions that are important to all New Zealanders.

**Summary of the first 12 months of the ADHB Maori Research Review Committee**

During its first 12 months, the ADHB Maori Research Review Committee convened 13 times and reviewed 128 separate research proposals, thus emphasising the significant amount of work involved in this process. The significant issues highlighted in the Committees’ reviews are presented in Table 1 (in 6-month blocks).

<table>
<thead>
<tr>
<th>Review outcomes</th>
<th>First 6 Months</th>
<th>Second 6 Months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No consultation</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>No consultation documentation</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>No definition of ethnicity</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Tissue handling and disposal</td>
<td>14</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>Maori Health Service contact details</td>
<td>38</td>
<td>23</td>
<td>61</td>
</tr>
<tr>
<td>Koha</td>
<td>5</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>Unvalidated questionnaires for Maori</td>
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<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Complex language patient information sheet</td>
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<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Intellectual property issues</td>
<td>-</td>
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<td>1</td>
</tr>
<tr>
<td>Approved without change</td>
<td>7</td>
<td>37</td>
<td>44</td>
</tr>
</tbody>
</table>

The principle areas highlighted by the Committee pertain to a lack of written documentation of consultation with the proposal, a lack of detail on patient consent.
tissue handling and disposal, and the inclusion of contact details for regional Maori health services.

The planned use of questionnaires developed outside New Zealand to examine psychological and other parameters in Maori, and the use of complex technical language in patient information sheets were also significant issues.

Table 2. Summary of the review outcomes for 128 proposals assessed by the Auckland District Health Board Maori Research Review Committee (stratified by the first and second 6 months of the Committees functioning)

<table>
<thead>
<tr>
<th></th>
<th>Changes Recommended</th>
<th>Approved Without Change</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>First 6 Months</td>
<td>47</td>
<td>7</td>
<td>54</td>
</tr>
<tr>
<td>Second 6 Months</td>
<td>37</td>
<td>37</td>
<td>74</td>
</tr>
</tbody>
</table>

Table 2 presents (in 6-month blocks) summary statistics for approved research projects, or where changes were recommended. It indicates an increasing proportion of research applications approved without change in the second 6 months of the Committees’ tenure (due to clarification of the goals and requirements of consultation).

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References.


Maori responsiveness in health and medical research: clarifying the roles of the researcher and the institution (part 2)

Andrew Sporle, Jonathan Koea

Abstract

Introduction The combination of the Health Research Council’s Guidelines for researchers on health research involving Maori and the 1998 revision of the National application form for ethical approval generated an expectation that all research development required consultation with Maori.

Methods and Results This paper clarifies issues of consultation for health researchers in two ways. Firstly, the historical development of the focus on the Maori research responsiveness is outlined. Secondly, we argue that research institutions, rather than researchers, need to take a lead role in consulting on research issues with Maori organisations.

Conclusions Consultation with Maori at the institutional level could help clarify and address key ethical issues in research—while reducing the workload for researchers, Maori organisations, and host institutions alike.

This paper attempts to clarify the issues regarding consultation with Maori (in the development of biomedical and clinical research), and follows an earlier paper reviewing nine key areas relevant to Maori responsiveness that can be readily addressed by researchers in their proposals.

In this paper, the development of the requirement for Maori responsiveness for health research is briefly outlined—to show that the Maori consultation process follows similar requirements to the rest of the health sector, and is unlikely to change in the foreseeable future.

Some institutional initiatives have been established to assist researchers developing proposals. However, research-focused consultation currently has not been developed at the institutional level, which (if implemented) would be an effective means of minimising the work of researchers and Maori communities/organisations alike, while generating a proactive set of clear research guidelines.

The development of the consideration of Maori responsiveness in Crown-funded health research

The consideration of Maori responsiveness in research is not new and has been driven by policy and legislative activities of successive governments for over a decade. The need to increase the contribution of health research to improving Maori health and accommodating specific cultural issues in the research process were raised by the official review of health research that recommended the creation of the Health Research Council (HRC).
The Health Research Council Act (1990) sought to address these issues via the creation of a Maori Health Committee as a standing committee of the HRC responsible for advising on research ‘into issues that affect Maori people, with particular reference to research impinging on cultural factors affecting Maori people’.\(^3\)

In addition, the Health Research Council Act required that the HRC Ethics Committee included membership with knowledge of tikanga Maori (Maori lore). These functions of the HRC were further reinforced by the 1996 Policy Guidelines from the Minister of Health to the HRC.\(^4\) These guidelines were intended to ensure that the HRC’s activities meshed with the current priorities of the rest of the health sector. In 1999, the Ministry of Research Science and Technology published its Blueprint for Change—a statement of policies and procedures for the whole of the Crown investment in research science and technology.\(^5\) This document set out ten key stewardship expectations for all Crown purchase agents against which their performance would be assessed. Responsiveness to the needs and diversity of Maori was one of these expectations.

The recent structural changes effected by the New Zealand Public Health and Disability Act 2000\(^6\) have reinforced the need for all aspects of the health and disability sector to be responsive to the health needs of the Maori population. As outlined in the New Zealand Health Strategy, the Ministry of Health wants information that will improve Maori Health, and the community wants research of relevance,\(^7\) thus making the Maori responsiveness requirement relevant to health research for the foreseeable future.

**Researchers and Maori responsiveness**

In seeking to determine the Maori responsiveness of their intended project, some researchers choose to consult directly with Maori researchers and/or organisations. Unfortunately, this creates an additional and un-remunerated workload for Maori researchers and organisations, distracting them from their own activities and (in the case of Maori researchers) contestable funding applications. The consideration of the Maori responsiveness of an intended research project involves several key steps, most of which are simple extensions of the usual processes in developing a research idea.

The first step is to consider the importance of the health issue for Maori. This can be included in the literature search and review—with Hauora\(^8\) and Our Health, Our Future\(^9\) being excellent starting points. Where published information is not available, anecdotal evidence may be available from clinical colleagues, or some information may be available from the New Zealand Health Information Service (NZHIS) or the local district health board (DHB).

If the topic is relevant to Maori health, then determining how to ensure the project can realise any potential contribution to Maori health involves learning from approaches used in prior or current projects in their own or similar fields. There is a rapidly developing experience in a range of Maori responsiveness strategies amongst mainstream researchers in the biomedical, clinical, and public health fields. A combination of consulting the literature and talking with peers is an efficient means of determining possible effective strategies for new projects. It also enables the possible use of other researcher’s pre-existing networks with Maori organisations.
The third step involves the identification of end-user organisations related to the research topic. Within the identified organisations, there may be Maori-focused sections or staff, or there may be specific Maori organisations with a dedicated interest in the proposed topic. As with any end-user relationship, working with Maori in such organisations (or Maori-specific organisations) benefits researchers by the application of their work, and by the possibility of a relationship that reaches across a range of projects. The relationship may also be useful in the development of research ideas, recruitment of participants, and dissemination of results. The benefit for Maori in these organisations is that they get to help develop research that is relevant and addresses their needs as a service or policy provider. The resulting research also has possibilities for the development of their workforce or even new services.

A fourth step involves the researcher referring to any institutional codes of practice on the Treaty of Waitangi or Maori responsiveness issues in research, especially if their project involves Maori as participants. Some host institutions for researchers have developed (or are developing) such codes of practice. If no guidelines exist, then researchers should consider lobbying their institution to develop locally relevant policies and procedures in line with the requirements of the HRC.

If significant research-related issues have not been clarified and resolved (by these processes), then researchers should consult with institutional-resource people. For researchers in DHB settings, this involves working through the issues with the research manager and/or Maori management staff in the relevant sections of the organisation. Some universities (eg, University of Otago) already have staff to work with researchers on Maori responsiveness activities—while others, such as Auckland University, have developed processes for pre-submission review of applications.

**A Maori consultation framework for research**

The stated intent of the HRC in publishing the *Guidelines* was to assist in the development of:

- Research partnerships between health researchers and Maori communities/groups on issues important to Maori health.
- Research practices, which ensure that biomedical, clinical and public health research effectively contributes to Maori-health development (whenever possible).
- Research practices that ensure, maintain, or enhance mana Maori.

The HRC guidelines were intended to provide advice to individual researchers rather than all persons involved in the research process. Efficiency and Treaty of Waitangi arguments indicate that much of the consultation should take place at the institutional level. Consultation with Maori is already a requirement of DHBs via the New Zealand Public Health and Disability Act—and Treaty of Waitangi issues feature in most University charters.

Currently, most of the consideration of Maori responsiveness issues occurs late in the research development process (once the research idea or even the design has been formulated). As a result, opportunities are missed, or researchers are faced with the prospect of additional work-amending research proposals late in development.
A possible alternative process is outlined in Figure 1, where the host institution is responsible for the consultation and for ensuring the Maori responsiveness of research activities.

**Figure 1.** A framework outlining the interrelationships between host institutions, researchers, Maori end-users, ethics committees, and mana whenua. (HRC=Health Research Council; FRST=The Foundation for Research, Science and Technology.)
Locating the responsibility for consultation with host institutions ensures that the universities and DHBs operate as Crown agents, and negotiate research polices and practices as part of their consultation and partnership activities with mana whenua (people with authority over the region).

In this model, the formulation of Maori responsive research policies and practices are a specific outcome of the operation of the Treaty of Waitangi relationship between the host institution and mana whenua. Such policies would then be available to all institutional researchers, and be able to guide research proposal development from its inception in a similar manner to other institutional policies.

These policies would involve institutional guidelines for researchers that could clarify acceptable practices regarding involvement of Maori participants, use of tissue samples, use of Maori genetic material in research, intellectual property issues with regard to indigenous flora and fauna, and when consent is required and how procedures for obtaining it.

The document could also outline unacceptable practices as well as practices that would require further consultation and negotiation to resolve. In the case of procedures for obtaining consent, it would also clarify the consultation mechanisms and points of contact that the institution or researcher would engage with. The policies could also include local research priorities for Maori wellbeing, relationships of mana whenua with any institutional ethics committees, and possibly even a co-ordinated approach to relationships with mainstream and Maori end-users for research on specific topics (e.g., National Heart Foundation and Te Hotu Manawa Maori for research on cardiovascular health and health services).

This approach would provide the institutions, ethics committees, and funding bodies with clear mechanisms for assessing the Maori responsiveness of an intended research project. It would also provide a way for Maori responsiveness practices to be developed via a combination of precedent and ongoing consultation. Where there is more than one research institution (e.g., a DHB and a university) within a region, this approach would enable to common local research policies to develop.

The researchers would benefit by having clear guidelines to follow that could be referenced in any funding or ethical application. Furthermore, researchers could then focus on the other determinants of their research interest, including their relationship to the endusers of their work. Consultation would be limited to those circumstances defined by institutional guidelines (which would be signalled well in advance), and institutional consultation mechanisms would be provided. This would also remove (from mana whenua and Maori organisations) the burden of multiple consultations from individual research proposals.

**Conclusions**

The introduction of Treaty of Waitangi considerations and Maori responsiveness requirements has been undertaken to ensure that the Crown’s investment in research science and technology contributes to Maori development whenever possible. Unfortunately, however, it introduced a further degree of uncertainty into the funding- and ethical-review application processes.
This uncertainty could be removed altogether by the provision of institutional policies on Maori responsiveness in research, especially if those policies were the result of institution-led consultation and negotiation with local Maori representative organisations. Such policies would also serve to guide the activities of ethics committees and funding bodies in their assessment of research proposals.

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Clinical practice guidelines’ development and use in New Zealand: an evolving process

Eileen McKinlay, Deborah McLeod, Antony Dowell, Catherine Marshall

Abstract

Aims This study explores the use of evidence-based guidelines by New Zealand general practitioners, and describes strategies developed to overcome identified barriers in the New Zealand setting.

Methods In-depth, semi-structured interviews with a purposeful sample of New Zealand guideline stakeholders including policy makers and general practitioners. Data were analysed using inductive thematic analysis. Feedback of emergent themes to the New Zealand Guidelines Group (NZGG) and further collaboration resulted in strategies to overcome barriers to use, some of which have now been implemented.

Results At the time of the research (2000/2001), general practitioners reported that they did not regularly use guidelines to support decision-making regarding patient care. Reasons given included guidelines formats not being recognisable or user-friendly, lack of general practitioner involvement in prioritisation and development processes, influence of stakeholders, and recommendations not being accessible or relevant. Policy and other interviewed stakeholders reported general acceptance of guidelines, however there were minimal interfaces between the NZGG and these organisations.

Conclusions Effective implementation of guidelines requires more than guidelines endorsement by policy stakeholders and passive dissemination strategies, but rather an understanding of the issues facing general practitioners and their attitudes to guideline use.

New Zealand (NZ) guideline development began around 1992 with various organisations funding guidelines on specific topics. In 1996, the New Zealand Guidelines Group (NZGG) was formed. This initiative was funded by the National Health Committee and based on the guideline development processes introduced by the Seattle Group Health Co-operative. The first initiative involved establishing a number of fellowships (for opinion leaders from a broad spectrum of clinical and consumer interests) to study guideline development in Seattle. Later, US and other international guideline developers were invited to NZ to run intensive training courses. The NZGG became one of the founders of the Guidelines International Network, which shares ‘evidence’ internationally.

Guidelines were seen as a way of introducing and promoting evidence-based practice. New Zealand government directives support the use of evidence-based practice and clinical practice guidelines. The original aim of the NZGG guidelines programme included formally training medical practitioners to undertake guideline development, and for these clinicians to develop evidence-based guidelines using the prescribed development process. An anticipated outcome was a movement towards an explicit evidence-based approach to health care provision (Figure 1).
Since then, clinicians from other disciplines (nursing, social work, community health workers, mental health workers, occupational therapists, and disability sector workers), consumers, and cultural representatives have undertaken guideline development training and been involved on guideline development groups.

General practitioners are considered an important target user group for the New Zealand guidelines that have been developed to date. Early NZ guidelines were often printed in full and disseminated by post to GPs throughout New Zealand with no other form of implementation. Although there is considerable international research literature regarding barriers to guideline uptake by doctors including general practitioners (GPs), little research has been undertaken in NZ.

Internationally, research literature identifies that there are barriers to the adoption and use of guidelines; including those guidelines that originate from the doctor or the structure they work in; or due to patient-related factors. Some doctors are hesitant to use guidelines; they are suspicious both of the philosophy and reasons behind them; and the content of the guidelines themselves. Whilst the literature strongly supports consumers’ using guidelines to inform themselves and their care, the impact and actual use of guidelines by consumers has not been evaluated.

Although many studies have been undertaken on implementation, and although universally it is agreed that implementation is pivotal in ensuring guidelines are used, there is no clarity about the most effective implementation methods.

In NZ, Thornley et al examined the effectiveness of postal dissemination of evidence-based guidelines on heavy menstrual bleeding. Prior to updating the recommendations on heavy menstrual bleeding, Park and Farquhar surveyed NZ GPs and gynaecologists regarding their current practice in treating heavy menstrual bleeding as well as perceived barriers to the recommendations of the 1998 guidelines.

Arroll et al determined the reported use and perceived usefulness of four national guidelines by New Zealand GPs. Factors included targeted clinician education
following dissemination, availability of the recommendations, and accessible decision support through the Adis New Ethicals (drug information) Catalogue.

Wynn-Thomas et al \(^8\) in their study of the use of the Ottawa ankle rules, surveyed NZ GPs about their use of selected New Zealand and international guidelines. GPs reported they ‘hardly ever’ or ‘never’ used guidelines in clinical practice. The effectiveness of the dissemination of the New Zealand Guidelines for the Diagnosis and Treatment of Adult Asthma was examined by Martin and Reid.\(^9\) Although guidelines were being (routinely) sent to all GPs; 2 weeks after it was sent, almost one-third of GPs could not remember receiving it.

In 2004, 46 guidelines have been posted in the NZGG guideline library, available on http://www.nzgg.org.nz In addition to NZGG sponsored guidelines, other independent guideline-developers continue to develop or update guidelines; many of these guidelines are also available on the NZGG website.

Primary care clinician acceptance and use of guidelines has been limited, and anticipated changes in clinical practice have not yet occurred. This study aimed to explore the barriers to guideline use by NZ general practitioners and to develop strategies to overcome identified barriers.

**Methods**

To gather information about guidelines and the use of guidelines by New Zealand clinicians, a literature search was undertaken. A literature review reference document was developed after searching for guidelines literature from the main databases—including Medline, Embase, CINAHL, and psycINFO. The review summarised the key themes from the available literature.\(^20\) Few NZ published or unpublished works were located. Any (unpublished) projects undertaken to evaluate NZ guidelines were identified and audited.

A purposeful sample of currently practicing New Zealand general practitioners (GPs)—representative of age, gender, years in practice, and urban/rural status—were invited to take part in this project. A purposeful sample of guideline stakeholders were invited to nominate a representative to be interviewed. Stakeholders included the NZGG, the Ministry of Health (MOH), the then Health Funding Authority (HFA, a health service purchaser now devolved into the MOH), PHARMAC (the New Zealand pharmaceutical regulator), and an Independent Practitioner Association (IPA, an organisation of GP providers).

Interview schedules were developed in collaboration with stakeholders. Schedules included open-ended questions about knowledge and use of existing guidelines; the role and importance of guidelines; and additional questions for GPs concerning their use of guidelines, perceived barriers and facilitators to the use of guidelines, and perceived consumer use of guidelines or other evidence-based information. Interviews were generally undertaken by one researcher in 2000/2001 and were either face-to-face, or via email or telephone if a face-to-face interview was not possible. Interviews were audio-taped and transcribed. GP interviews were continued until data saturation was reached.

Data from interviews were analysed using inductive thematic analysis, identifying themes either held in common or disparate between those interviewed, and themes that coincided or were different from the literature. Emerging themes were discussed by the research team. The results were presented to the NZGG Board and strategies were developed to address a number of issues identified from the data.

In collaboration with the Department of General Practice at Wellington School of Medicine and Health Sciences, strategies were identified, and a number of initiatives have since been undertaken by the NZGG to enhance end-user acceptance of guidelines. In addition, the research team developed a guideline evaluation framework\(^21\) based on the AGREE model.\(^22\)

**Results**

Five stakeholder organisations were asked to nominate a representative for interview, and 13 currently practicing general practitioners (GPs) were approached to be
interviewed. All those approached, agreed to participate. GPs ranged in experience from a newly started practitioner through to one nearly retiring. They were representative of urban and rural practice and from both the North and South Islands.

At the time the interviews were undertaken, NZGG was an evolving organisation. A new full-time Chief Executive had been appointed, and several guidelines were ‘in production’. The reason for wanting to foster development of guidelines included ‘having assurance of a robust process to determine the evidence around the relative efficacy of clinical treatments’ and to ‘ensure that the general public were receiving interventions or services that would be of maximum benefit’. It was also hoped that guidelines could be used to advocate for access to the most effective forms of treatments (including cost effectiveness), even if sometimes this could require changes in prescribing regulations and pharmaceutical schedule funding. (NZGG believed that guideline development and use would contribute to a cultural shift over time towards the use of research evidence in clinical practice.)

The HFA believed guidelines had the potential to improve overall care, including the provision of consumer information, thus giving patients an expectation of care delivery. The HFA viewed the NZGG as an independent body with expertise and networks.

The MOH believed that evidence-based guidelines were one of a range of tools which could be used to enhance the appropriate quality and standards of the health service. The MOH believed that they should be responsible for creating an environment where guidelines were seen as useful tools. However, they did not believe it was their role to develop structural processes or to sponsor implementation of a specific quality improvement method to enhance guideline usage.

PHARMAC perceived NZGG’s main role as the development of evidence-based guidelines, and supported the use of guidelines in general, particularly those which met their funding/affordability objectives. The development of evidence-based guidelines appeared to influence funding decisions that PHARMAC made. However, PHARMAC recognised there was an inevitable tension when guidelines were released containing pharmaceutical recommendations that PHARMAC could not fund, or when there was a lag time in funding a guideline pharmaceutical recommendation.

At the time of interview, the IPA had no formal interfaces with the NZGG. They believed that ideally they should have an interface with the NZGG and identify clinical practice issues for consideration as guideline topics. IPAs had developed their own guidelines and education/implementation strategies for members, which they felt were effective. They noted that general practitioners preferred to use locally developed IPA guidelines, possibly because of their involvement in development and recommendation of services available locally.

**New Zealand GPs’ use of (and attitudes to) guidelines**

The key themes (to emerge from interviews with GPs) related to GP recognition of guideline formats; stakeholder endorsement; prioritisation of guideline development; GP information overload; guideline implementation issues; the relevance of guideline recommendations to general practice; and GP participation in guideline development groups.
GP recognition of guideline formats—Visual recognition of guideline documents within NZ appeared to be low with confusion between evidence-based guidelines and quasi guidelines or other information produced and disseminated to GPs by drug companies or interest groups.

Stakeholder impact—Endorsement by professional colleges or other professional networks was perceived to have a positive influence on the recognition and possible uptake of guidelines. Conversely, influence by Government or other health regulatory organisations was viewed negatively. GPs expressed concern that guidelines could be linked to contracts and that failure to comply with guidelines may have medicolegal implications.

Guideline development prioritisation—GPs were uncertain whether current NZGG guidelines met their need for evidence-based information, and believed the process of prioritising topics for guideline development was unclear. Furthermore, they believed that they needed to be involved in this prioritisation process through GP organisations (such as IPAs).

Information overload—The GPs reported that they were overwhelmed by the written material sent via post and electronically—with some Wellington GPs in 2000 having to read as much as 52 pieces of postal mail per day (excluding email). Newly arrived guidelines have to compete with patient-related and other essential information. GPs also reported difficulty in establishing effective storage and management systems for hardcopy guidelines, which inhibited timely retrieval.

Implementation issues—The interviewed GPs felt that effective implementation was essential to enhance the uptake of guideline recommendations. They did not feel that postal dissemination of guidelines (on its own) to GPs had been effective. Implementation strategies such as working in conjunction with stakeholders to locally redevelop and implement national guidelines were suggested. Short education programmes within scheduled GP organisation or peer review meetings and one-to-one practice education (academic credentialling) were also suggested.

Relevance of guideline recommendations to practice—Many of the GPs interviewed saw it as unfortunate that there were several recommendations made within the NZ guidelines (which were not relevant to their practice or were inaccessible, or out of the scope of, their practice) thus reflecting a stakeholder objective in developing the guideline to change policy rather than practice. An example frequently cited by general practitioners was the recommendation in the Guidelines for the treatment and management of depression by primary health professionals to use cognitive behavioural therapy in the treatment of depression, when this therapy was neither publicly funded nor freely available. Another example was the recommendation (made in the Guidelines) to use tranexamic acid for the management of heavy menstrual bleeding when, at the time the Guideline was released (and for some time after), this medication could only be prescribed by a specialist gynaecologist or obstetrician.

GP participation in guideline development groups—GP participation in guideline groups was viewed as onerous because of the time commitment involved through undertaking guideline development training, meeting time, and work required in between meetings. For GPs who had never been involved in guideline development, there was a perceived lack of GP involvement in guideline development teams, and
(when GPs were known to be involved) a lack of a defined process for GP selection. GPs felt they were not consulted whilst the guideline was being developed.

Implications: NZGG initiatives to address barriers to guideline use

Strategy to ensure recognisability of NZGG guidelines—A uniform and recognisable appearance/brand has been developed for guidelines sponsored by the NZGG. Documents now routinely include abbreviated formats and consumer information. The NZGG logo is prominently displayed along with the logos of supporting organisations and professional bodies. This allows practitioners to easily differentiate between NZGG guidelines and guidelines developed by specific interest groups, therefore providing quality assurance.

Strategy to identify stakeholders—NZGG has established strong links with appropriate stakeholders to ensure goals are congruent and acceptable to guidelines end-users. Stakeholders nominate members to the guideline development teams, and are invited to peer review draft guidelines and comment on the penultimate version of the guidelines as part of the formal endorsement process.

Strategy to address guideline development priorities—The NZGG attempts to closely monitor possible need for guideline development though contacts with their funding bodies. To a large degree, the priority topics have been driven by the NZ Health Strategy or those areas where the greatest gap between current practice and evidence-based practice has been perceived. NZGG is working with the Ministry of Health to set up a process for liaising with stakeholders to discuss priorities for the future, although there is no guaranteed funding for priority area guideline development.

Strategy to address the need for appropriate information—The NZGG are attempting to provide additional print and electronic formats that enhance different reading styles. Summary sheets are available in hard copy and electronic format. Online access is available, and some IPAs are providing GPs with the NZGG guidelines and other information on CD-ROM. NZGG are now producing several information resources for consumers and other provider groups.

Strategy to address guidelines implementation issues—NZGG strongly supports the implementation of guidelines, and now requires guideline-development groups to also develop an implementation strategy. However, they acknowledge their dependency on funders to also support implementation. (In the past there has been no mandate for funders to routinely implement new guidelines.) Currently, several Primary Health Organisations (PHOs) are using the guidelines to build their primary care preventative programmes. In addition, other organisations such as IPAs, the Best Practice Advocacy Centre (BPAC), and the Goodfellow Unit (Department of General Practice and Primary Health Care, University of Auckland) have used the guidelines as base resources to develop CME programmes.

Since 2001 implementation strategies have been increasingly tailored according to the guideline topic and the end-user population. At regional and national meetings of healthcare practitioners, NZGG actively promote the main messages from guidelines.

A typical implementation strategy targeting GPs might now include: dissemination by post (in conjunction with material known to be read by GPs such as the biweekly medical newspapers); wide national and medical media coverage of the
recommendations; PHARMAC- and District Health Board-funding (aimed at raising awareness of evidence-based strategies); development of a brief laminated guideline summary; guideline promotion at the RNZCGP or similar conferences; working with Consumer magazine to produce an article on the guideline recommendations for consumers; commissioning a patient-information resource; and running Continuing Medical Education (CME) sessions and sponsoring online CME.

**Strategy to ensure there is relevance of guideline recommendations to clinical practice**—Guideline-development groups now liaise with the Ministry of Health and other regulatory bodies (including Medsafe and PHARMAC) throughout the guideline-development process. Guideline-development teams are also asked to provide practical guidance to readers where there may be treatment or care options that are not affordable or accessible in NZ, and to make recommendations that are suited to the current NZ setting. Guidelines are also ‘road-tested’ before publication and when any impractical recommendations are identified, these are reviewed, and action is taken (where possible) to see if systemic changes can be encouraged to bring effect to the recommendations.

**Strategy to address the involvement of GPs in guideline development teams**—An independently appointed NZGG project manager now supports each development group. As many aspects of the guideline development process as possible are transparent, with guideline members disclosing vested or competing interest. Critical appraisal of literature relating to a clinical topic is now generally being undertaken by expert researchers rather than the development group themselves (which happened in the past). The NZGG has formulated a new evidence-grading system to include high quality qualitative research. This approach is important to enable the inclusion of evidence from cultural groups.

There is now greater flexibility in timelines for guideline development, recognising that some clinical topics are complex to address. Generally speaking, NZGG are trying to speed up production of guidelines by taking the main bulk of the work away from the guideline-development team members. For example, clinicians are now routinely nominally paid for work undertaken in guideline development groups.

**Discussion**

Since 1998 and the formation of the NZGG, increasing numbers of guidelines have been developed and disseminated for clinicians to use. The NZGG has fostered a robust, internationally recognised, evidence-based guideline-development process; and has rigorously protected the process.

There have been few evaluations of the impact and outcomes of guidelines produced and disseminated to New Zealand GPs. Those evaluations which have been undertaken suggest that the impact of guidelines has not been as substantial as hoped for.

Whilst there appears to be adequate knowledge around, and processes to undertake development of, ‘evidence-based’ guidelines; there has been a considerable knowledge-gap regarding the attitudes of NZ clinicians towards and current use of guidelines—including which guideline formats and implementation methods work best for NZ clinicians and consumers.
This qualitative review of the New Zealand guidelines movement has identified a number of issues impacting on guideline use by GPs. However, there are limitations in this study. The size of the sample may limit generalisability, and qualitative methods identify the range of opinion rather than the proportions of stakeholders who hold any given attitude. Nevertheless, the themes reported here recurred independently across interviews, and are consistent with international writing on guidelines.

New Zealand guideline-development appears to have been predominantly funder-rather than clinician-driven and this may have influenced the acceptability of the guidelines to GPs. Funders have initiated guideline-development for various reasons, primarily based on the need to close a perceived gap between current practice and evidence-based practice but also as a mechanism to drive policy changes. It is unfortunate that currently there is no formal mechanism for GPs to signal the need for guideline development on a particular topic.

Use of guidelines in the past to drive policy changes has lead to the inclusion of recommendations for pharmaceuticals and treatments that cannot be accessed by GPs—this has caused frustration for GPs. Lack of early liaison with stakeholder/regulator groups (including PHARMAC and the MOH) has exacerbated these issues. In addition, there is ongoing dialogue about whether recommendations (which promote interventions that are not available in NZ) should be included in a NZ guideline, even if they are recommended as ‘best’ practice.

In New Zealand, previously there has not always been a formal estimation of current practice prior to guideline-development, and clinical topics have been identified as priorities for guideline development without having this baseline information. Therefore it has been unclear whether NZGG guidelines have been effective in closing the gap between current- and evidence-based practice, or whether in fact the gap exists as a result of lack of knowledge of best practice or as a result of resource constraints or other factors.

NZGG have recently worked more closely with stakeholders in planning an overall guidelines strategy. Involving organisations such as the Royal College of General Practitioners and GP organisations potentially increases guidelines relevance for GPs. It is unfortunate that some early NZ guidelines were not well received by clinicians because of their format and/or their recommendations, and clinicians may have become averse to considering recently released guidelines. NZGG now informs stakeholder groups about any guidelines work in progress, and notifies them when to expect the release of new guidelines. This means that CME events can be arranged in advance. Unfortunately, the volume of guidelines being sent to GPs is still substantial (5 guidelines were released in 2002; 7 guidelines, 16 summaries and 1 evidence report completed in 2003, and 7 guidelines and 7 summaries anticipated to be completed in 2004). Thus, some mechanism whereby GPs can prioritise new guideline information and can request selected evidence summaries is still required.

In the past, there has not been a systematic process to implement guidelines in New Zealand. Guideline development groups have not been routinely funded to develop an implementation strategy and no single body has held responsibility to ensure implementation was occurring. Although guidelines are formally launched and
disseminated by post to practicing clinicians, and some may receive media and other attention at the time of release, generally there is no ongoing formal implementation.

There is a substantial body of international literature on implementation, including literature that is specific to primary care. In summary, studies of guideline implementation have demonstrated that, despite positive attitudes towards guidelines, there is variable to low usage. However, the potential perceived by stakeholders (for guidelines to provide an effective vehicle for disseminating new information) drives continuing examination of different implementation strategies.

Meta-analyses and reviews conclude that different implementation interventions are effective under some circumstances, but none is effective in all circumstances. Implementation strategy must be planned, tailored to specific barriers to change and targets set.

Although NZGG undertake the Agree Collaboration process for evaluating the rigor of guideline development, this model does not incorporate a formal evaluation of the effectiveness of dissemination and implementation. A model developed by the research team (based on the Agree Collaboration model) also includes an evaluation of the guideline topic selection process and the effectiveness of dissemination and implementation.

In the 2 years since this data was collected, and in response to the project recommendations (based on international guideline research), the NZGG has actively attempted to address clinician barriers to using guidelines by various measures described above. There is a further commitment to addressing clinician barriers through implementation and by working more closely with practicing clinicians to determine professional needs that can be met by guideline development.

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‘All about research’—looking back at the 1987 Cervical Cancer Inquiry

Barbara Heslop

Every year on August 5, members of the Auckland Women’s Health Council gather in the grounds of National Women’s Hospital to commemorate the anniversary of the release of the Cartwright Report and to remember the women who died as a result of the ‘unfortunate experiment’.

The Council’s newsletter pages http://homepages.ihug.co.nz/~awhc/newslett.htm have this to say (February 2004):

‘In more recent years we have also remembered others – in 1999 the premature babies who were part of the chest tapping physiotherapy at the hospital, and in 2000 the women of Gisborne. Last year, a wreath of yellow daffodils was placed around the statue to acknowledge the Gisborne women whose lives were lost or damaged as a result of a cervical screening programme— which did not do what it was set up to do…’

‘Following the ceremony in front of the statue, the party walked around the back of the hospital to a pohutukawa tree marked by a plaque, which was laid in 1993 in memory of Dr Bill McIndoe, cytologist and colposcopist at the hospital from 1963–1983; and Dr Malcolm McLean, pathologist at the hospital from 1961–1988. The tree and plaque were placed beside a path in the hospital grounds near what used to be the Colposcopy Clinic where Dr McIndoe worked and was overlooked by Dr McLean’s Pathology Laboratory…’

‘…the Inquiry itself and the subsequent Report marked the end of an era of medical paternalism and arrogance which was allowed to reign unchecked.’

My knowledge of the Auckland Women’s Health Council derives from its webpages. Apart from the fact that I live at the other end of the country, my medical academic background gives me a somewhat different perspective of the events commemorated by the Auckland Women’s Health Council.

The Cartwright report, of course, recorded the findings of the Cervical Cancer Inquiry held in 1987. Specifically, this inquiry related to the circumstances surrounding an unorthodox approach to treating cervical dysplasia and carcinoma at National Women’s Hospital (NWH) in Auckland by Dr G H (Herb) Green. A professional paper (Obstet.Gynecol.1984; 64:451-458) published after Green’s retirement by NWH staff members (pathologist Malcolm [Jock] McLean, colposcopist and cytologist Bill McIndoe, and others), discussed the outcome of Green’s management of his patients. This paper was brought to the notice of Sandra Coney and Phillida Bunkle, who in 1987 published an article in Metro magazine entitled An ‘Unfortunate Experiment’ at National Women’s, which eventually led to the official inquiry chaired by Judge (later Dame) Silvia Cartwright in 1987. The official report of the Inquiry, issued in 1988, is the report to which I refer below.
A couple of years ago, I found myself discussing the Cervical Cancer Inquiry with a group of 3rd year medical students in Dunedin. At the time when the Inquiry was held, most of these students would have been 5 or 6 years old. Between 1999 and 2002, I had returned to the university (teaching pathology to 2nd and 3rd year medical students) as a retired staff member helping out temporarily during a staffing crisis.

The third year of the medical course in Dunedin has for the last few years included a session that I first encountered in the student programme as ‘Integrative Day – Cartwright’. As a graduate from a different era, the ‘Patient Doctor and Society’ part of the course, in which this session figured, was new to me. So ‘what was the Cartwright session about?’ I asked my student group (because at that stage they would have known little about cervical carcinoma). ‘It was all about research,’ was the reply.

I thought that I knew a little about medical research. Apart from directing my own transplantation immunology research group for several years, I had been a member of a couple of the first assessing committees when peer-review assessment was instituted by the Medical Research Council (MRC) in the early 1970s, and I had later (for several years) chaired the National Scientific Committee of the Cancer Society of NZ, which at the time funded most of the country's cancer research. I also knew a bit about histopathology, one of the ‘bones of contention’ at the Cervical Cancer Inquiry—in fact, I had done nothing else for a period of 8 years in New Zealand and London.

Despite the extensive nature of the investigation, it had always seemed to me that parts of the research side of the picture were missing. I doubt whether filling the relevant scientific gaps would necessarily have made much difference to the recommendations of the Inquiry. But the missing information might have explained the apparent lack of intellectual sophistication that not only allowed the ‘unfortunate experiment’ to get started in the first place, but also prevented it from being terminated much earlier than it was. Conceivably, it might have tempered some of the opprobrium to which Herb Green—seemingly a bewildered old man at the time of the inquiry—was subjected. But by the same token, it would also have asked why the pathologist and colposcopist took so many years to make a point that they were probably very well placed to make much earlier.

I have taken the opportunity to look at the New Zealand medical research scene in the 1950s–1970s because, although these were very exciting years for biologists, at the same time a lot of medical research, and especially clinical research, was relatively unsophisticated and unstructured. A substantial re-appraisal of research methodology followed the introduction of formal peer-review by the Medical Research Council in the early 1970s. Scientific assessment became a very different procedure from some of the so-called review processes that had operated previously. Knowledge of the basic biological processes that underlie disease was very limited in the 1950s and 1960s, relative to the huge expansion that was to come, and this was reflected in much of the research that was carried out at that time. So the session that my students had reported as being ‘all about research’ concerned an event that I had always seen as thin on the scientific side. I was more inclined to interpret it as being ‘all about peer review’, and to an even larger extent—embarrassingly—it was ‘all about some of the ignorance and intellectual naivety of a previous age’.

**Terminology**—In talking about cervical lesions, I’ll use the simpler terminology of today’s undergraduate pathology classes—ie, dysplasia for all the relevant non-
invasive lesions of the cervix, and carcinoma (or cancer) for the invasive lesions. Since the hallmark of malignancy (cancer) is invasive growth, unless I am quoting others, I'll avoid using that contradictory term carcinoma in situ—CIS (‘a cancer lacking the hallmark of cancer’), and call it severe dysplasia instead.

Today’s model of neoplastic (tumour) growth has been around since the mid 1980s. It views all the relevant cervical lesions as resulting from a series of genetic mutations, whose occurrence lacks any consistent pattern—hence the clinical variability. The mutations affect a wide assortment of genes, which in their normal (unmutated) state mostly control cell growth. Invasion supervenes when a set of mutations (the ‘metastatic cascade’) provides the altered cells with the biological ‘know how’ to travel beyond their normal confines. The early mutations, whose occurrence is reflected in the cytological features of dysplasia, increase the probability of further mutations, including the potentially lethal ‘metastatic cascade’. Dysplasia can, nevertheless, persist for many years without supervention of the ‘metastatic cascade’.

The above conceptual framework of neoplasia (see Scientific American July 2003, for a brief account) does much to explain the variable and unpredictable relation between dysplasia and invasive cancer. The model was in its very early days at the time when Herb Green retired. I mention it here because those people re-reading the report of the Inquiry may find it easier to think along these lines than to get too enmeshed in the different (and often confusing and contradictory) terminologies prevailing at the time of the Inquiry.

Medical research between 1950 and the mid-1970s

I’ll start by considering the background against which this all occurred. I qualified in medicine in 1948 – three years after Herb Green, and in the same year as Malcolm (Jock) McLean. Bill McIndoe graduated shortly after this. We were all students of Sir Charles Hercus, for whom the promotion of research in the Otago Medical School was a mission. The extent to which he succeeded was summarised by Prof John Ludbrook, an Otago graduate working in Australia, in his article written on the occasion of the Medical School centenary in 1975 (N Z Med J. 1975;81(533):133–4). Not surprisingly in this environment, all members of staff and all aspiring academics were encouraged to become involved in research. This was fine—if you had any idea how to go about it. Most of us did not.

Research training: then and now—Today’s intending medical researchers are usually enrolled for a research degree, and have mentors and official supervisors. The problems to be investigated and the students' approach to them will be approved before they start, and monitored along the way. Research trainees will learn how to test a scientific hypothesis, how to present their findings, and how to defend their conclusions in the face of possible criticism. Only a little of this sort of training was available at undergraduate level in our day, and only in the medical sciences. Not surprisingly, most students of our vintage graduated with major scientific deficiencies. How well we made good the deficiencies probably depended on how quickly we identified them. There was often an element of luck in this—it depended on our chosen fields, what we read, who were our seniors and mentors, and to some extent on chance encounters.
Human biology on the eve of the golden age—By today’s standards, the general public in the 1940s and 1950s was almost unbelievably ignorant of human biology. Virtually no biological sciences were taught in secondary schools; what there was, consisted mostly of botany taught in a few girls’ schools. Polite conversation was delicately non-specific about biological topics, and this vague gentility served to perpetuate the underlying ignorance. Thus, the Auckland newspapers during the war referred to ‘social diseases’ for what we would now call ‘sexually transmitted diseases’. Needless to say, there was no sex education in schools at any level. At university in Dunedin in the 1940s, the annual lecture to 5th year medical students on contraception was crowded with students from other faculties. Among many of the general public, bowel diseases and cancer were scarcely mentionable.

Against this social background, those who were familiar with anatomy, physiology, and pathology spoke a different language from those who were not. This partly accounts for some of the medical paternalism and condescension of the time, although it hardly excuses its grosser manifestations. Of all people, the distinguished biologist JBS Haldane (described by Nobel laureate Peter Medawar as ‘In some respects … the cleverest man I ever knew’) was not told by his London surgeon about the spread of his cancer—an omission that had significant effects on his subsequent plans. His sister, writer Naomi Mitchison, duly complained to the British Medical Journal about this (see JBS. The Life and Work of JBS Haldane by Ronald Clark; Oxford University Press, 1984).

Quite apart from doctors’ attitudes to ‘telling’ or ‘not telling’ (which varied among my contemporaries), withholding bad news was often viewed as kindness. Margaret Forster’s Good Wives? (Vintage, 2002) describes the measures taken in his own household in the 1960s to keep Aneurin Bevan, architect of the British National Health Service, from finding out that he was dying of cancer. Arrogance and paternalism? Sometimes, but these accusations need to be considered in the context of their day.

Experimentation and the golden age of biology—The 30 or so years after the war saw the dawn of the current golden age of biology, with DNA as its incomparable opening fanfare in 1953. On the medical scene, antibiotics and better anaesthesia opened the door to procedures that had previously seemed impossible. Thus, the postwar years were a time of unprecedented medical experimentation. A vivid account of the medical research climate then and now, and of the spectacular advances that were achieved at great cost, can be found in the obituary of Francis D. Moore, one of America’s major players—perhaps the major player—in the surgical dramas of those times (New Yorker, May 5 2003). The obituary goes on to describe the complete change in his attitude in the 1970s. To some extent, this attitudinal change reflected a worldwide zeitgeist—triggered by revulsion at the human experimentation carried out in Hitler’s Germany, and revealed at the end of the war.

But the scrutiny was not restricted to clinical experimentation—it came to extend to virtually all aspects of medical practice. I mention the Francis Moore obituary here, because the same climate change (albeit a little later in arriving) took place in New Zealand.

New Zealanders as research ‘loners’—A significant, and probably increasing, proportion of today’s clinical research is done by large multidisciplinary teams and
multinational collaborative programmes. The situation in New Zealand in the 1950s–1970s, and especially in clinical research, was the exact opposite. Whether they wanted to or not, medical researchers often found themselves working alone. Today’s communications (e.g., fax, email, internet) did not exist. Geographic isolation and the cost of overseas travel added to the isolation. Medical scientists were slightly better off than clinicians. They usually worked in university departments, and their juniors were likely to be research students. The corresponding juniors in hospitals were mainly studying for specialist college qualifications and were often not particularly interested in research. For those who have to work alone, informed argument and criticism become luxuries, when in reality they are necessities.

**Collections as clinical research**

Clinicians looking for research projects during the years 1950–1970 could find it hard to get started, and they often ended up working on their own. One option was to study as many examples as possible of a given disease or procedure. In the first instance, this might entail accessing the hospital records and ‘taking out’ all the relevant cases. Later on, with growing clinical experience, and perhaps with a published analysis of the records, it might be possible to attain some local standing as an expert. It was easy enough to keep adding to the collection as cases became available, and to examine different aspects of the relevant topic, including the effects of different treatments. These studies were unlikely to have been designed as experiments, but were more in the nature of ‘wait and see what crops up and then write it up’. A new treatment in those days would have been seen as an extension of the therapeutic armamentarium rather than as an experiment.

The publications arising from a clinical collection were, of course, retrospective analyses. They had the shortcomings that go with this approach—especially the variability of the data and the difficulty of making comparisons. These faults were not always appreciated in the 1950s and 1960s, when some substantial research reputations were built up in this way. Publications arising from large collections of cases usually conferred some local cachet on the author, and an international specialist journal carried more clout than a New Zealand journal.

Indeed, getting published in an overseas journal was sometimes equated with having ‘an international reputation’. Once the writer had attained this status, referrals were likely to increase, and with any luck his (in those years it was seldom her) collection would snowball. By this stage, his opinion was seldom challenged. The main difference between the collector and his non-collecting colleagues lay in the propensity of the collector to collate his results for publication.

*As far as I am concerned, Herb Green’s research was an ongoing collection of clinical cases.* In asking his colleagues in 1966 to refer patients, he clearly had to tell them why, so he presented the relevant staff meeting with an overview of what he proposed to do. Managing these patients was always going to entail an element of ‘playing it by ear’—so it is quite conceivable that there never was a detailed experimental plan of action, of the kind that we would expect today. The proposal ostensibly related to an alternative treatment plan, and was probably seen at the time as no more than an extension to Green’s therapeutic repertoire. For many doctors, trying out a new treatment that they had read about, or offering a new skill that they
had acquired while on study leave overseas, was simply part of keeping up with things. Nevertheless, the observations accumulated by a clinical collector were almost certainly destined to be collated and published as a retrospective analysis, which would ultimately, at least in a teaching hospital, find its way into the departmental annual report as research. Doctors undertaking similar procedures without publishing their findings were unlikely to get mentioned in research reports. Ostensibly, they did not do research. We would look at things differently today, but that was how it was in the 1960s.

There is nothing wrong with amassing a collection of cases. People with a special interest in a given condition will tend to do this, and will often be extremely well-informed and highly experienced practitioners. Indeed, even retrospective observational research (the clinical descriptions of SARS, for instance) can still be very useful. But for the most part, by the 1960s and 1970s, large-scale retrospective analyses had had their day as research projects. There were better ways of collecting and presenting data. By the early 1970s, it would have been almost impossible to submit an ongoing collection as a research proposal using the format introduced by the MRC (Medical Research Council—currently the Health Research Council).

**Some scientific questions about Herb Green's research**

I now consider some of the scientific aspects of Herb Green’s research. The Cervical Cancer Inquiry took place in 1987 and related to clinical and histological investigations, which had had their origin a generation earlier. My familiarity with both research generations prompted me to ask four questions relating not only to the science of the period, but also to the understanding of some of the science, which I suspect to have been rather less than was assumed at the Inquiry.

**Proving a hypothesis?**—I am almost certain that Herb Green did not know that a scientific hypothesis has to be falsifiable. After reading the report of the Inquiry, and also Sandra Coney’s book (*The Unfortunate Experiment*; Penguin, 1988) which provides some additional transcripts from the Inquiry, I concluded that only a small minority of the New Zealand players in this drama (the epidemiologists) clearly indicated that they knew this. The references in the Inquiry to proving a hypothesis left me feeling very uneasy about the level of understanding of many of the other participants.

The word ‘hypothesis’ is often used by all of us to mean no more than ‘a sort of idea’. Strict scientific usage requires that a hypothesis be testable and falsifiable. Indeed, in contradistinction to what is widely assumed, a scientific hypothesis cannot be proved. At best, one can obtain evidence that is consistent with it. This information is sufficiently basic to figure in today’s secondary school biology syllabus (and it certainly did not figure in secondary school science in the 1930s and 1940s). Thus, Herb Green’s aim of proving that cervical dysplasia does not lead to invasive cancer should have entailed falsifying this contention. This should not have taken very long—whatever time it took to record the first case of invasive cancer.

I have read and re-read the relevant pages of the report of the Inquiry trying to ascertain whether Herb Green knew this. All the evidence leads me to conclude that he did not. This sort of misconception can be sorted out quite easily in an informal student class, or at a departmental seminar, but it can cause enormous difficulty in the
context of a formal inquiry, when not only is it central to the whole investigation, but when it is not officially identified as a problem.

Thus, while Prof David Skegg (*Report of the Inquiry*, pp32–33) commented on the inconsistencies in Green’s approach, had his investigation been set up with the aim of disproving a hypothesis, I suggest that Green himself never knew that he was supposed to be falsifying anything. Rather, I think that he intended to accumulate a large series of cases in which dysplasia had persisted for years without malignant transformation, and in due course to record his observations retrospectively.

If I am correct, Herb Green would probably not have appreciated the points made by David Skegg at the Inquiry about falsification. Furthermore, he (and ? his chief Prof Bonham) could have been bamboozled by the discussion of whether the word ‘invariably’ had been used in relation to the proposal that he submitted to the medical staff in 1966. A few years later, such a misconception might have become apparent during the course of MRC scientific assessment.

Pre-cancerous conditions (of which cervical dysplasia is one of many) increase the likelihood of developing a specified type of cancer. The concept is statistical—it is a matter of probabilities. As Kolstad indicates (*Report of the Inquiry*, p23), the evidence that supports classifying a condition as pre-cancerous, is circumstantial. We do not usually expect to observe the actual transformation of the original lesion into a cancer.

Herb Green aimed to ‘prove’ his hypothesis by carefully observing that dysplasia did not lead to cancer—and that was how it was presented to the medical staff in 1966. Unfortunately, the proposed methodology was equally appropriate for showing that dysplasia did lead to cancer. Paradoxically, and I am sure unintentionally, he ended up demonstrating (via the paper by McIndoe et al in 1984; *Report of the Inquiry*, Appendix 7) more convincingly than had been done before, the transition of dysplasia to cancer. I do not for a moment think that any group of New Zealand doctors would ever have condoned a clinical management plan that entailed watching cancers develop. Those attending the 1966 meeting at NWH simply did not see the proposal for what it was.

If Herb Green was under a misapprehension about scientific hypotheses, I doubt whether too many of his NWH clinical colleagues were any better informed. None of the medical staff seemed to see that the whole approach to Green’s hypothesis was ‘back to front’, as it were. A misconception like this, if it occurred, is no more than a commentary on the general state of scientific sophistication of those people at that time. Most of the clinical medical staff would, after all, have had little reason to ponder over the formal approach to a scientific hypothesis. This involves a mind-set rather different from that of routine clinical practice, and certainly different from that usually prevailing at staff meetings with multiple agenda items.

To those inclined to say ‘they should have seen it for what it was!’, I agree that it would have saved all sorts of trouble. Nevertheless, over 20 years later, comparable scientific shortcomings appeared to be widespread at the Cervical Cancer Inquiry. (Otherwise, why did nobody seize upon the points raised by David Skegg, and ask whether the NWH approach was an appropriate way of dealing with a scientific hypothesis?)
The medical staff, and particularly Herb Green, have been accused of all sorts of arrogance in rejecting criticism. Whatever part the personalities of all the participants in the Inquiry did, or did not, play, the lack of scientific sophistication—in my opinion the central problem—had its genesis in ignorance rather than arrogance.

There is a certain piquancy in noting that Karl Popper, the distinguished philosopher who established that a scientific hypothesis should be falsifiable, was working in Christchurch at the time when most of us were students. Physiologist Prof J C Eccles (a future Nobel laureate) invited him to Dunedin to speak in his department.

**Making predictions from hypotheses**—Also apropos of scientific hypotheses, I wondered whether anybody at NWH in the 1960s and 1970s realised that a scientific hypothesis should *generate predictions*? Herb Green had hypothesised that severe dysplasia was a different disease entity from invasive cancer.

If this were so, it could have been predicted not only that:

(a) Severe dysplasia could occur on its own (which was already known), but also that

(b) Invasive carcinoma could occur on its own, ie in the absence of associated severe dysplasia.

Therefore, I wondered whether Herb Green's hypothesis might not have been approached from the ‘other end of the disease spectrum’ by attempting to falsify prediction (b) above?

Herb Green is said to have regularly disparaged the specialist opinion of histopathologist Jock McLean. Most pathologists subjected to this sort of thing would have been hopping mad. But viewed from afar, it is pertinent to ask whether Herb Green might have done this simply because he belonged to that group of aggressive players who rather enjoy ‘trading intellectual punches’? Might it have been possible to beat an aggressive Herb Green at his own game? I think so.

The falsification of the prediction that cancer could occur on its own without severe dysplasia would have dealt a mortal blow to Green’s hypothesis. A purely histopathological investigation into which no clinical input was required, need not have involved Herb Green at all, so the exercise could have been free of verbal punch-ups. As long as the hospital had retained its hysterectomy specimens (and most hospitals would have done so in those days), it should not have taken too long to answer the question: *How frequently is unequivocal invasive cancer accompanied by severe dysplasia in the adjacent cervical epithelium?*

The two pathological lesions were already known to be associated—indeed, Jock McLean himself referred to NWH material showing the association (*Report of the Inquiry*, p76). More information was needed from the NWH cases on *how often* dysplasia accompanied cervical cancer. The existing literature already hinted at a figure not too far from 100% (references cited in the 2nd edition of R A Willis’s *Pathology of Tumours* (Butterworth, 1953—the virtual bible on neoplasia in its day). The demonstration that invasive cancer did not occur in the absence of severe dysplasia of the adjacent epithelium could have provided compelling evidence that the two lesions were related.

Such an investigation should not have been too difficult to carry out. With any luck, most of the relevant information would have been available on existing slides without...
calling for the preparation of more sections. Even at the slow rate of one specimen examined in detail each day, it would not have taken long to accumulate results from, say, 50 consecutive cases of cervical cancer. The findings would almost certainly have been publishable in a peer-reviewed international pathology journal. With suitable high-quality photomicrographs to illustrate the basis of the diagnoses, the conclusions would have been open to scrutiny by all, and could have supplied a reference point against which future discussions of this contentious project were considered. Once the information had been published, it would have been irrelevant whether Herb Green believed the results.

So why was it not done? I don't know, but my guess is that (like Herb Green) Bill McIndoe and Jock McLean had not given much serious thought to scientific hypotheses. It was a missed opportunity, but it could hardly be called anybody's fault.

A Eureka experience?—My next question concerns the origin of the hypothesis which Herb Green set out to prove, and to which he adhered so tenaciously. I was looking for the sort of information that in later years would have appeared in the Justification section of a standard research grant application—a detailed account of the evidence that led him to believe that some of the histological changes interpreted by most pathologists as being sinister were, in fact, innocuous. Epithelial dysplasia elsewhere in the body (mouth, skin, colon, for instance) has for a long time been regarded as pre-cancerous, although in some situations, many years can elapse before a cancer develops. Indeed, it may never do so. Green had, of course, already had a patient with a high-grade smear who had refused treatment, and who had nevertheless survived for many years in good health. He was no doubt acquainted with the slow progression rate of some other dysplastic lesions. A comparable behaviour pattern of cervical dysplastic lesions might offer a potential rationale for avoiding hysterectomies.

Green’s postulate that cervical dysplasia was relatively innocuous was, of course, ultimately going to require an answer to the question: ‘If it is not a pre-cancerous lesion, what is it?’ I suggest that Green had a pretty good idea of what the lesion was, but that his interpretation was wrong. He knew that histological sections of the foetal cervix often showed lesions very similar to adult cervical dysplasia and cancer. Thus, he argued that dysplasia in the adult might represent *persistance of a foetal structure*. And because the foetal lesion clearly did not lead to cervical cancer in childhood or adolescence, he deduced that the adult lesion was therefore less dangerous than conventional gynaecological wisdom deemed it to be. This interpretation accords with several pieces of evidence from the inquiry:

Paragraph 1 on p34 of the Report quotes Herb Green as saying,

‘Around about 1963 I thought of the possibility that abnormal cytology in women later developing CIS (= carcinoma *in situ* or severe dysplasia) or cancer may have been present at birth: this was because many pathologists and clinicians whom I consulted, diagnosed dysplasia or CIS in autopsy specimens of cervixes of stillborn infants’

It was an unusual idea, which should have provoked all sorts of discussion about the validity of the interpretation. It called for a contribution from histopathologists who had had experience with foetal and neonatal tissues, and possibly also from a developmental biologist. Unfortunately, New Zealand had not too many of these
people at the time. Thus, I was curious about the identity of the ‘many pathologists and clinicians’ said to have made the diagnosis. Not many autopsies are normally carried out on stillborn babies. Nor are many histopathologists very interested in examining the foetal cervix. Anyway, whatever Herb Green had seen in the tissue sections no doubt prompted him in 1963 to start looking for the corresponding ‘abnormal cells’ in vaginal smears from newborns. No abnormal cells were found in the smears. The intellectual isolation of the day meant that (as far as I can tell) nobody asked the important question ‘Why not?’ It might have led to a more critical appraisal of the tissue sections.

If the neonatal smears were uninformative, the evidence from the tissue sections remained important. At least two patients in the 1966 series (Report of the Inquiry, p33) were told about it:

*Patient code 4F1:* ‘He (Dr Green) told me that there was 9 out of 10 women have cancer and he said that in my case, if I went to my normal GP they would panic…. They would be rushing me into hospital…. and he says in cases like that, it does lie dormant…. ‘

*Patient code 4S:* ‘Every person is normally born with cancer, but it is the type of cancer that is dormant….He said sometimes it just flares up every now and then…..’

Although patients’ recollections are prone to inaccuracy, I doubt if two people could independently have come up with the same very unusual story that ‘we all have cancer but it lies dormant’, had they not actually heard something very like it.

As late as 1979, Herb Green noted (in NZ Med J. 1979;89(629):89–91):

‘Some observations (unpublished) by the present author on the histological features of the cervical epithelium of infants dying at or around term have shown appearances which some pathologists (without knowing the source of the material) have been prepared to describe as at least dysplastic if not neoplastic’.

Oddly, and tantalisingly, Herb Green did not publish any representative photomicrographs. Inexplicably in the circumstances, nor did anybody else at NWH seem to make a point by referring to photomicrographs. Yet they were at the time easily obtainable. So we are left guessing what Herb Green had seen in the foetal cervix. I suggest that he almost certainly saw the early phases of squamous metaplasia—a benign but actively developing lesion, occurring at a time when the foetal cervix was already engaged in the normal growth spurt that occurs before birth.

The process is described in some detail in Yao S Fu’s *Pathology of the Uterine Cervix, Vagina and Vulva 2nd edition* (Saunders, 2002). Metaplasia involves the conversion of one type of epithelium into another and is fairly common in the cervix from late foetal life to the 8th decade. While Herb Green was no doubt very familiar with its *adult* manifestation, in which the mature squamous cells are easy to
recognise, the immature cells in the early stages of the foetal lesion are a more
difficult diagnostic problem. Indeed, as Yao Fu points out (Figs 2-22 and 2-23) the
appearances superficially resemble the lesions seen in adult cervical dysplasia, or
even invasive cancer, for which they can be mistaken.

Thus, I suggest that Herb Green’s ‘dormant cancer’ idea stemmed from his failure to
realise that metaplasia in the foetus was a different lesion from adult cervical
dysplasia. From his 1979 comment (above), it appears that he was not alone in
thinking this. Yao Fu’s photomicrographs, incidentally, probably explain why Green
failed to identify ‘abnormal’ cells in vaginal smears from neonates – the relevant cells
were deeply situated, and would not have been detached during the preparation of the
smears.

It is easy enough to be disdainful of this whole idea today, especially with the
advantage of being able to view things within the conceptual framework of the current
model of neoplastic growth (which has dysplasia a few mutations away from cancer).
This was not possible in the 1960s, when Green’s ideas would have looked
considerably less ‘way out’ than they do today. Nothing highlights the downside of
intellectual isolation more tellingly than this story. Indeed, his hypothesis should have
brought the devil’s advocates out of their laboratories.

Instead, apart from some unidentified pathologists, who did not know the source of
the material (referred to in his 1979 publication), the only record of any
communication seems to have been with a couple of patients. Anybody who has
worked in isolation will know how easy it is to become devoted to a misconception,
especially if it has involved something of a Eureka experience—one of those ‘highs’
that reward researchers for having what at the time seems to be a great idea.

Notwithstanding the intellectual isolation in which Herb Green worked, it remains a
mystery to me why none of his colleagues were acquainted with the ‘dormant cancer’
idea.

Was it because he was better informed than his colleagues on cervical histopathology,
so did not bother to discuss it with them?

• Because he told them about it, but they were not very interested, or it did not
  register with them?

• Because nobody ever asked him what evidence had prompted the 1966 hypothesis
  (by then his 1963 neonatal vaginal smear project had probably been forgotten)?

• Because he did not want to be asked why the ‘abnormal cells’ present in the foetal
cervical tissue sections did not show up in the newborn vaginal smears?

• Because he suspected that GPs, as well as his own colleagues, might have
  panicked when they heard the “dormant cancer” idea?

Maybe there is a grain of truth in all these possible explanations.

Scientific peer review: then and now—The inquiry raised the subject of inadequate
peer review on several occasions but was vague not only about the process, but more
importantly about who should be doing the reviewing and when. The expectation that
Herb Green’s clinical colleagues had the know-how to evaluate some scientific
aspects of his contentious investigation was, I think, unrealistic. Scientific assessment
underwent a radical change in New Zealand during the early 1970s. For all practical purposes, New Zealand adopted international practice. Something very different had obtained before this.

The apparent lack of understanding of the process of scientific peer review, and what it entailed over the relevant period, was a gap in the Inquiry as far as I was concerned.

To provide a standard against which to consider the so-called assessment carried out in 1966, it is useful to outline the process set up by the Medical Research Council in the early 1970s. This represented the country’s first attempt at systematic scientific review. Research proposals were submitted in a standard format that basically asked what was being done, why it was being done, how it was to be done, what staff were involved, whether their qualifications were appropriate, what benefits were likely to accrue from the study, how long it was likely to take, what it was going to cost, and so on. Furthermore, a proposal was typically supported by up-to-date references from the relevant literature.

All the MRC committee members were experienced researchers. A research proposal was first considered by two committee members who provided preliminary written reports. In the general discussion that followed, all the other committee members commented individually, and the opinions of national and/or international referees were made available. A numerical score, using the designated MRC scale, was finally assigned privately by each member. Neither the applicant for a grant, nor any of his/her associates, was ever present in the room while the proposal was being discussed.

Within the limits of what is possible in a small country, the members of the four committees were selected for their knowledge of a given field. Thus, a molecular biologist would not usually be a member of the clinical committee, and vice versa. Reviewing a grant application could be time-consuming if it called for ‘nitpicking’ checking of data or journal references, or if it entailed writing a balanced report on a contentious application. Formal assessment of this type is simply not the business of the usual medical staff meeting.

Research funding organisations such as Cancer Society, National Heart Foundation, Neurological Foundation, Arthritis Foundation, and so on, subsequently adopted the MRC format. Most of the funding for university and hospital biomedical research has (for many years) come from the above sources—so for the last 25–30 years, it has been almost impossible to gain a significant research grant without submitting an application along these lines.

In a recent (2003) personal communication, Jim Hodge (formerly Director of the MRC) who instituted this assessment process, commented:

‘In retrospect, I think the most important thing that I did during my time with the MRC was to persuade (?) force the council to adopt a proper peer review system. The members had naively assumed that appointing a professional as
Chief Executive Officer would solve all their problems of assessment of research quality; and it took some time and effort to persuade them otherwise.’

It was a hugely important move and changed New Zealand medical research irrevocably for the better.

**Scientific peer review pre-1970s**—Prior to the institution of individual project grants, the MRC used to provide block grants to academic departments, the disbursement of which was the responsibility of the departmental head. Such peer review as there was at the time, took place at departmental seminars or institutional research meetings, at national and international meetings, and finally when the work was published.

For an individual researcher, the extent of the peer review was apt to be variable, and depended on the culture of the department or institution. Medical sciences departments were more likely than clinical departments to hold regular research meetings, and junior scientists were usually more likely than junior clinicians to argue with their seniors.

When individual project grant applications replaced most of the departmental block grants in the early 1970s, preparing a formal application turned out to be a much more demanding task than contributing a section of the departmental annual report, which had until then constituted the main communication with the MRC for those of us who were not departmental heads. The informed national and international criticism to which most of us were now to be individually subjected (via our grant applications) no doubt sharpened our intellectual faculties more effectively than almost any other relatively simple administrative change could have done.

**Herb Green and the Medical Research Council?**—It seems almost certain that Herb Green’s research was never submitted for assessment by the MRC. Amassing a collection of cases costs nothing, so there is no need to apply for financial support. The former Director of the MRC (Jim Hodge) and Deputy Director (Colin Geary) have both confirmed that Green never held an individual project grant from the MRC (personal communications 2003). His work had started in the days when funding was via departmental block grants, and Green did figure as an associated investigator, and later as a principal investigator, in some of the annual reports to the MRC provided by Prof Bonham.

All departmental research activity was apt to find its way into the annual reports, irrespective of whether it had used MRC funds. Although Herb Green’s research was said to have been ongoing, his name appeared in some annual reports but not in others. Indeed, in the personal communications (2003) referred to above, neither Jim Hodge nor Colin Geary is certain why the Inquiry (p64) reported that Herb Green’s research was assessed by the MRC in 1982. Since he did not hold a grant, the MRC would have had no reason to assess his work.

**Our theories may be wrong but our data must be right**—Some of the data relating to the Cervical Cancer Inquiry leave me feeling uneasy—at least from this distance. For at least some of the time period covered by the investigation, it appears that for a number of patients, two different histological diagnoses (McLean, Green) had been made on the basis of the same cervical lesion. The in-house investigation undertaken at NWH in 1975 had its origin in a conflict about these histological diagnoses. So who
made the definitive diagnosis? When? Which diagnosis is in the hospital records? When did it get there? And which one appeared in those hospital records that were examined in 1975 by the in-house investigating committee (Drs Macfarlane, Faris and Seddon)?

Since the inquiry recorded that the in-house committee of investigation had no terms of reference, what did its members know about the histological disagreement and the memos relating to it? Did the differences of pathological opinion involve only dithering on the basement membrane—ie, the decision on whether there was micro-invasion. (This is a comparable problem to the harder ‘run out’ decisions by the 3rd umpire in cricket. It concerns difficult borderline situations open to differences of opinion.) Or did it involve major diagnostic disagreements?

The absence of photomicrographs in a couple of situations that seemed to be calling out for them is strange. For histopathologists, they exemplify the aphorism that one picture is worth 1000 words. One photomicrograph with an arrow pointing to the lesion of interest, and accompanied by the caption: ‘The arrow marks the lesion interpreted by A as … and by B as …’ would have been more effective than a dossier of memos. Photomicrographs were easy enough to obtain in the 1960s and 1970s, so why did nobody bother?

Maybe it is possible to resolve the data about which I feel uneasy into a set of clear unequivocal results. But that calls for better access to the data than I have.

**For my former student group—the salient points**

My students are supposed to leave class armed with the salient points of the topic under discussion. So the scientific pieces that were missing from their ‘all about research’ session go something like this:

- Herb Green’s 1966 project exemplified the relatively unsophisticated approach to clinical research of many of his vintage of medical graduates. He almost certainly had a major misconception about scientific hypotheses. Had comparable ignorance not been widespread among his professional colleagues, the investigation could have been concluded quite quickly (in months?).

- The investigation was basically a collection of clinical cases whose attributes were to be reported retrospectively. The 1966 proposal was a request for more referrals to try a new treatment. He explained why he wanted the referrals—but this was not a formal project application as we write them today.

- New Zealand had no formal system for scientific peer review of research proposals before the early 1970s. This was a defect of the age. Even if such a system had existed, the hospital staff were not qualified to evaluate some of the scientific issues raised by Herb Green’s hypothesis. And scientific peer review (as opposed to ethical review) is a usually a function of one or other of the research funding organisations.

- The conservative treatment of cervical lesions was prompted partly by the known long duration of some pre-cancerous lesions, but also by his misinterpretation of cervical histology from stillborn babies. This misconception was not helped by the relative isolation in which Green worked. Strangely, his clinical colleagues were almost certainly unaware of the evidence underpinning Green’s conservative
treatment. It was never published in a way that could be properly evaluated. Today’s standard model of neoplastic growth had not at the time been developed.

- It costs nothing to collect clinical cases, so there was no need for a research grant. The work thereby escaped a good deal of early scrutiny. Green never held an individual MRC project grant and his work was never assessed by the Council. He featured in some of the annual reports of the MRC because the head of his department held a block grant from the Council, which called for an annual report. All departmental research activities were apt to figure in these reports, irrespective of whether they used MRC funding.

- To those who ask if scientific naivety and ignorance is a bad thing—of course it is. But the scientific glass-house in which we all live has walls as thin as the cover slip on a histology slide, so throwing stones is not particularly useful. However knowledgeable we might seem today, we are all doomed to be overtaken in our own fields tomorrow. It is easy enough to see Herb Green as the fall guy for his era of clinical research.

- In failing to take into account some important changes that had taken place between the 1960s and 1980s, the Inquiry missed identifying the scientific problems that were central to the whole affair.

**Some more trees**

Coming back to the tree at National Women's Hospital: Trees are lovely things—we should plant more of them. I'd plant one to remind an institution that suffered as a result of the inquiry, that it has hosted some of the country's top biomedical scientists.

Indeed, I’d add another tree to thank all the staff—yesterday’s and today’s—for caring for thousands of patients over the years. Hospitals are safer places when they retain some *esprit de corps*, and when the staff can feel that their work is appreciated.

And please, a tree to remind everybody that Jim Hodge instituted the sort of peer-review assessment that halted inferior investigations before they got off the ground—a system that all the larger research funding organisations in the country duly copied a few years later. I am keen on this tree because many people in this country give generously to medical research. I would hate them to think that we are not deadly serious about what we do with their money. Also apropos of scientific peer-review assessment, another tree would acknowledge the overseas experts who review this country's grant applications. They work behind the scenes and give of their time and expertise for nothing.

Somewhere in this grove I’d like to record two comments on research. Specifically, and in relation to medicine, clinical research is undertaken simply because the current diagnosis and/or treatment are not good enough. In a more general sense, we should carve the message into stone that it was research—finding out—that brought our ancestors out of caves.

**A final question**

We teach our pathology students that in biology, as elsewhere, ‘there is no such thing as a free lunch’. Thus, an account of a vitally important process like inflammation always comes with the questions: What harm does it do, and what does it cost?
Turning to the Cervical Cancer Inquiry, undoubtedly it righted some wrongs. But what harm did it do, and what did it cost? Perhaps 16 years is long enough after the event for somebody (who knows more that I do about the current O&G scene) to scan the balance sheet dispassionately.

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**Acknowledgment:** This account of medical research in the third quarter of the last century owes much to discussion and correspondence with my contemporaries. As might be expected, their research experience has varied. Some have been academics, and this group includes distinguished international endocrinologist Mont Liggins. Many others have belonged to a group that I’ll call inadvertent researchers—clinicians who introduced new treatments in their day, only to find a later generation classing their way of doing things as research. I hope that they will agree that this was how it was.

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**Reference:**

Early intervention for psychosis in New Zealand

Mark Turner, Susan Nightingale, Cecilia Smith-Hamel, Roger Mulder

Psychosis is defined as a primary disturbance of thinking, which is reflected in certain symptoms—particularly disturbances in perception (hallucinations), disturbances in beliefs and interpretation of the environment (delusions), and disorganised speech patterns (thought disorder).

There are multiple causes of psychosis—including substance abuse, exposure to severe stress, inherited and acquired medical conditions or diseases, and mood disorders. Historically, the outcomes for those with psychosis have generally been thought to be poor.

Early intervention for psychosis

In recent years, there has been a growing interest in the concept of early intervention for psychosis. Wyatt’s influential paper reviewed 22 studies in patients with schizophrenia. This review suggested that poor outcome (long associated with an insidious onset) had as much to do with delayed use of antipsychotics as the illness process itself. Wyatt concluded that early intervention with neuroleptics in first-episode schizophrenia patients may increase the likelihood of improved long-term course.

Three types of early intervention for psychosis have been described: primary prevention, secondary prevention, and tertiary prevention.

Primary prevention

Early intervention before or during the prodromal phase involves indicated primary prevention and should lead to a decrease in the incidence of psychosis. Several groups are currently researching the feasibility of designing screening procedures to identify those with an ‘at risk mental state’. Authors widely acknowledge the existence of early specific and non-specific signs preceding the first psychotic episode; however, they have yet to clearly demonstrate their ability to predict and specify the transition to psychosis leading to clinical and ethical concerns about initiating (antipsychotic medication) treatment at this stage.

Secondary prevention

Secondary prevention means intervention in the early stages of the development of a psychotic disorder, during the prodromal phase or onset of the first episode. While secondary prevention may be initiated before the development of frank psychotic symptoms (ie, during the prodromal stage), the majority of services concentrate on reducing the ‘duration of untreated psychosis’ (the period from the onset of psychosis to the implementation of ‘adequate treatment’). Several studies have reported that the longer people remain psychotic before beginning treatment, the more likely they are to suffer relapses. Patients gain less benefit from receiving maintenance antipsychotic medication, and from intense treatment.
Further, long delays (between the onset of psychosis and treatment) are associated with greater cognitive impairment, more severe negative symptomatology, and poorer personal and social outcomes. Recognition and intervention at the earliest possible stage of florid psychosis could contribute to earlier symptom remission, delay in relapse and prevention of psychosocial deterioration.

**Tertiary prevention**

*Tertiary prevention* is not an early intervention strategy and has more to do with the timing, duration, and content of adequate treatment aimed at reducing the morbidity of the disorder. Along with considerations of the importance of the duration of untreated psychosis, evidence is also emerging of a ‘critical period’ for vulnerability to relapse and development of secondary handicaps during the first 3 years following the onset of a first psychotic illness.

Birchwood et al have suggested that when disabilities develop following a first episode of psychosis they usually do so during the first 3 years. Unemployment, impoverished social networks, and loss of self esteem can develop rapidly during this ‘critical period’. The longer these needs are not dealt with, the more entrenched they become. It has therefore been proposed that timely and effective intervention at this stage might alter the subsequent course of the illness and reduce the social toxicity of psychosis.

Early intervention for psychosis in the New Zealand context generally involves recognition and intensive phase-specific intervention from the time the individual becomes psychotic (although many services will accept those with a suspected prodromal presentation). This involves a combination of secondary and tertiary prevention strategies. In this case ‘early’ refers to treatment ‘earlier than usual’ in order to reduce the duration of untreated psychosis (secondary prevention). The ‘intervention’ is comprehensive, intensive, phase-specific and individualised treatment for these individuals aimed at reducing the morbidity associated with first episode psychosis (tertiary prevention).

Early Intervention for Psychosis (EIP) services aim to provide intensive multidisciplinary treatment during the early phase of psychosis (typically in New Zealand for the first 2 years, although international research indicates that 5 years may be more appropriate).

Briefly, EIP services should provide:

- An early detection programme.
- Use of appropriate low-dose atypical antipsychotics and other medications as appropriate.
- Psychoeducation.
- Family interventions.
- Cognitive behavioural therapy for acute phase/persistent symptoms.
- Motivational interviewing for substance abuse.
- Social interventions.
- Assertive outreach.
A key document outlining the style of service provision for New Zealand services is the *Early intervention in psychosis: guidance note*.

While *early* intervention is considered advantageous to optimal recovery, a consistent finding from the literature is that the duration of untreated psychosis is long, with a median of approximately 26 weeks. Examination of the help-seeking behaviour of individuals with first-episode psychosis suggests that the individual and their family members may try a number of times to obtain help before adequate treatment is obtained.

One of the important aspects of EIP services is an early detection programme and in this regard, General Practitioners and other social agencies have the potential to play a crucial role.

**Relationship to general practice and other agencies**

A large part of the delay in referring people with first episode psychosis is associated with the non-specific and insidious nature of the early signs of psychosis.

Key features that may indicate the presence of psychosis or its prodromal stage include:

- Marked unusual behaviour.
- Feelings that are blunted or seem incongruous to others.
- Speech that is difficult to follow.
- Marked preoccupation with unusual ideas.
- Ideas of reference—things having special meanings.
- Persistent feelings of unreality.
- Changes in the way things appear, sound, or smell.

Lester provides a useful checklist on what to look for in a GP consultation for first episode psychosis. She concludes that it is important to not just ‘wait and see’ what happens, or to dismiss symptoms (such as social withdrawal as part of adolescence; or as secondary to drug misuse). People with suspected first episode psychosis should be referred to early intervention services for further clarification of symptoms, and appropriateness for early treatment. Further guidelines for GPs are available online from [http://www.eppic.org.au/resources/earlydiagnosisbooklet.html](http://www.eppic.org.au/resources/earlydiagnosisbooklet.html)

In Australia, the average GP will have 3-4 patients with schizophrenia at any one time, and might be involved in the diagnosis of 4-5 patients with schizophrenia in their career. International estimates suggest there are approximately 11 new cases of psychosis per 100,000 population per year.

The main problem is that prodromal-like symptoms are extremely common in adolescence and early adulthood, and health professionals must decide whether symptoms are just normal adolescent behaviour—or something more serious. The non-specific nature of symptoms combined with a low incidence rate means that primary healthcare professionals may overlook this diagnosis. However, it is estimated that half of the people with first episode psychosis have had contact with a
GP prior to commencing effective treatment. Preliminary data from Totara House Early Intervention Service (in Christchurch) indicates that in the 6 months prior to referral, 60 out of 122 people with first episode psychosis had contact with a GP. Eleven (18.3%) of these people were referred to treatment at Totara House (Turner; unpublished data; 2004).

This high rate of contact with GPs makes them an important group to target with regard to any effort to reduce the duration of untreated psychosis. In New Zealand, and in many other countries, most people with first-episode psychosis appear to present to EIP services through acute inpatient services.

Totara House figures show that 54% of clients are referred following admission, and a further 19% from the Psychiatric Emergency Service at Christchurch Hospital. This suggests that the early signs of psychosis are unrecognised, and that people are only being seen once inpatient treatment is required. Of particular concern is the fact that the early signs of psychosis in Maori (and Pacific Peoples) may be missed by health practitioners, and that Maori (and health professionals) may reframe psychosis in a cultural context (Mason Durie; personal communication; April 2002).

To examine issues associated with the early identification and treatment of psychosis, New Zealand is currently involved in an international study examining GPs knowledge of first-episode psychosis. The results of this study will help service development for primary healthcare professionals involved in the management of early psychosis. This research is timely given the move to a primary mental health care strategy.

While General Practitioners, in particular, have an important role to play as ‘gatekeepers’ for early identification of first episode psychosis, there are many other agencies who may be able to detect the first signs of a developing psychotic illness (or at least notice that ‘something is not quite right’ and make appropriate referrals). For example, follow-up and follow-back studies have shown that teachers are capable of identifying individuals who later develop serious mental illness including psychosis. Others include school guidance counsellors, personnel managers with major employers, and a range of counselling and support agencies. Identification of pathways to care and education aimed at these agencies should be seen as a priority in New Zealand early intervention services.

**Early intervention for psychosis services in New Zealand**

A further potential barrier to early referral to specialist EIP services is the lack of knowledge of the existence of such services. There has been a steady growth of specialist services that work with people with first episode psychosis. In 2000, there were 18 statutory mental health services that work, wholly or partly, as early intervention services for young people. Twelve of these were established in or after 1998, through funding following the *Mason Report*. A systematic survey was conducted by the authors on the availability of EIP services in New Zealand. A detailed description of each service is available on the Internet from the Mental Health Research and Development Strategy website: [http://www.mhrds.govt.nz/files/4_29_71_98_EIP.pdf](http://www.mhrds.govt.nz/files/4_29_71_98_EIP.pdf)

Overall, New Zealand’s main city centres are able to deliver quality care utilising the principles of EIP services. Services appear to be well-informed and familiar with the
literature—and they are adapting it well to their local conditions. However, there are many other areas with enthusiastic early intervention staff frustrated by the lack of resourcing and support/understanding from those unfamiliar with the principles of early intervention.

Improving the responsiveness of mental health services is one of the five service delivery areas on which the Government wishes the health sector to concentrate in the short-to-medium term. In addition, the targeting in this strategy of public health and primary healthcare provide the platform for the emergence of early intervention for psychosis as a central consideration for mental health services under the New Zealand Health Strategy.

Public health initiatives aimed at mental health promotion and increased co-ordination between primary healthcare providers and secondary service providers (such as early intervention services) are core requirements of the Government’s strategy.

EIP services are an important response to the increased awareness and acceptance of mental illness promoted by public health campaigns such as the ‘Like Minds Like Mine’ project. ‘…the inclusion of prevention activities highlights the growing importance and contribution of early detection towards the effective management of mental health problems and of improved community mental health outcomes…’

Projects aimed at reducing the stigma associated with mental illness may mean that people are more likely to seek help when (or even before) a crisis develops. This may be particularly beneficial for professionals who identify symptoms but then face resistance from clients regarding referral for appropriate assessment.

Similarly, with the development of public education, the various support agencies are likely to become better informed about the signs of first-episode psychosis, and about the availability of EIP services. Should this prove to be the case, appropriate services ought to be available to meet this increased demand.

The dual developments of early intervention for psychosis and public education may have an increasing impact over the next generation as the New Zealand Health Strategy is implemented. However, evaluation of the efficacy of these programmes is necessary to ensure the money is well spent.

Conclusion

A review of the literature suggests that early intervention for psychosis is successful in reducing the initial morbidity and distress associated with the first psychotic episode; however, it is unclear whether it leads to better long-term outcome. There is evidence that the earlier treatment is given following the onset of psychosis, the more favourable the outcomes—at least in the short term. This implies that attention should be paid to reducing the duration of untreated psychosis by providing education to those professionals who may come in contact with people who are experiencing first-episode psychosis.

EIP services can be justified clinically; it is sensible to treat people with first-episode psychosis (as soon as possible after symptoms develop) with intensive, comprehensive treatments. Whether it is superior to existing treatments remains unclear. A feature in the British Journal of Psychiatry debated whether ‘early
intervention for psychosis is a waste of valuable resources'. The article concluded that they remain, at least, an example of 'basic aspects of good practice in the management of psychotic disorders' (page 196).

In summary, EIP services have a significant positive effect for clients while in treatment. Although there is still insufficient evidence regarding the long-term benefits of early intervention services, we recommend referring clients to these services where they are available.

Furthermore, early referral to specialist services may lead to better outcomes for those with first-episode psychoses—particularly earlier psychotic and negative symptom remission, less psychosocial deterioration, and increased treatment adherence.

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Missed opportunities for better health outcomes in New Zealand

Harvey White

In a country such as New Zealand, which has many different ethnic groups and many rural communities, it is a considerable challenge to achieve equity of access to medical services. Although it is not possible to provide every small community with immediate access to every medical service, it is one of the founding principles of our health system that access to healthcare should be equitable, and thus the elimination of socioeconomic, geographical, and ethnic inequalities should be central to health policy.

Age-standardised coronary heart disease (CHD) mortality has fallen dramatically in New Zealand since 1970—by 61% in men and by 56% in women. It is commonly assumed that almost all of this reduction has come from primary prevention. However, US and UK studies have calculated that treatment advances accounted for 75% of the reduction in CHD mortality in the USA in the 1980s and 42% of the reduction in England and Wales between 1981 and 2000. (The UK reduction appears less dramatic because this study did not count secondary reduction of risk factors as a treatment benefit.)

Since 1970, Australia’s reduction in CHD mortality has outstripped New Zealand’s by 23% in men (75% versus 61%), and by 29% in women (72% versus 56%; Figure 1).

Figure 1. Comparison of coronary heart disease mortality rates in Australian and New Zealand men between 1950 and 2002

[Graph showing comparison]

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Before 1975, New Zealand’s CHD mortality rates were approximately 13% lower than Australia’s, but now our mortality rates exceed Australia’s by 28% in men and by 24% in women. These percentages represent more than 1200 deaths annually that would not occur if New Zealand’s mortality rates were commensurate with Australia’s.

Although there are probably multiple reasons why New Zealand hasn’t done as well, changes in the ethnic makeup of our population are unlikely to be a cause. Both countries have made good progress in cutting smoking rates, but Australia has probably been more successful in improving its citizens’ dietary habits.

Neither country has made much headway against obesity, lack of exercise, and the increasing prevalence of diabetes—but Australia has achieved substantially higher revascularisation rates, performing 27% more angioplasties per capita than New Zealand in 2002. Australia has also enjoyed more timely access to newer and better pharmaceuticals, introducing 112 new drugs that New Zealanders have been denied over the past 6 years. It speaks volumes that Pharmac’s budget has not increased since 1998.

There are also marked outcome gaps for Maori. For example, Maori women aged 45–74 have 21% higher CHD mortality rates than Pakeha men. Moreover, Maori and Pacific patients have a greater prevalence of CHD than other ethnic groups, but are far less likely to have angioplasty or bypass surgery. As Bramley and colleagues commented in a recent issue of the Journal, a specific Maori cardiovascular health action plan is clearly needed to help close the outcome gap.

Coronary heart disease is the commonest cause of death in New Zealand women, killing four times more women than breast cancer. Yet women are less likely than men to be referred for cardiac rehabilitation or to undergo revascularisation procedures. In the USA, heart disease now kills more women than men. Preventive programmes are needed to target risk factors specifically in women.

The practice of evidence-based medicine helps to minimise both over- and under-treatment, and to identify the cost-effectiveness of treatments. All too often, however, New Zealand has delayed the adoption of new knowledge into routine clinical practice while we watch the evidence accumulate—and then when the evidence becomes too overwhelming to ignore any longer, we say it is ‘too expensive’.

Conservative treatment certainly has its place, but if our treatment guidelines and practices lag behind current knowledge, we are practising second-rate medicine and perpetuating inequalities in healthcare.

The recently reported Cardiac Society audit of acute coronary syndrome management is unique in that it involved every centre throughout in New Zealand, and all physicians willingly shared their data. Because physicians controlled and collected the data, it is probably highly accurate. There is also likely to be a much stronger feedback loop, encouraging the use of evidence-based therapies in response to any deficiencies identified by the audit.

According to current evidence-based guidelines, aspirin and either unfractionated or low–molecular-weight heparin should be given to all patients (without treatment contraindications) with non–ST-elevation acute coronary syndromes and elevated cardiac biomarker levels, and glycoprotein IIb/IIIa inhibitors should be used in all
high-risk patients without contraindications. At present, however, only 83% of patients in interventional centres and 77% in non-interventional centres receive aspirin, only 70% and 57% respectively receive heparin, and only 3% and 2.6% respectively receive glycoprotein IIb/IIIa inhibitors.

The most compelling of the audit’s findings is that New Zealand’s usage of these therapies is markedly lower than in comparable international registries. The recent Global Registry of Acute Coronary Events (GRACE)\textsuperscript{13}—involving Argentina, Australia, Austria, Belgium, Brazil, Canada, France, Germany, Italy, New Zealand, Poland, Spain, the UK and the USA—found that internationally 60% of non–ST-elevation myocardial infarction (MI) patients had angiography (versus 42% in interventional New Zealand centres and 16% in non-interventional New Zealand centres), 33% internationally had angioplasty (versus 20% and 3% respectively), and 9% internationally had bypass surgery (versus 4% and 2.1% respectively).\textsuperscript{13}

The Cardiac Society audit unequivocally documents major deficiencies and inequalities in our delivery of healthcare. Several factors have been identified. First, we have resource limitations in both equipment and personnel, as identified by the recent national cardiology resource survey.\textsuperscript{14} Second, not all hospital formularies include modern evidence-based pharmaceuticals such as clopidogrel, enoxaparin and glycoprotein IIb/IIIa inhibitors. Third, opinions differ about the magnitude of benefit, supporting evidence, adverse event profiles, and cost-effectiveness of these therapies—although they are recommended by international guidelines, including the Cardiac Society’s.\textsuperscript{12} Fourth, opportunity costs may differ between centres; eg, in some centres a decision to forego access to a particular therapy may liberate sufficient funding to employ a cardiac rehabilitation nurse, whereas in other centres there may be fewer competing priorities. Fifth, practical issues such as access to (and transportation for) angiography and revascularisation obviously have a greater impact in some centres than others.

Clearly, there are major resource limitations throughout New Zealand with respect to the provision of cardiac catheterisation and revascularisation facilities. To achieve parity with international norms in the GRACE registry, New Zealand would need to triple our current angioplasty and bypass surgery rates in patients with non–ST-elevation MI. And even the international rates in the GRACE registry are low considering the strong evidence of benefit and cost-effectiveness (including a 22% reduction in hospital readmissions) when patients undergo invasive treatment coupled with intensive antithrombotic therapy.\textsuperscript{15}

The Cardiac Society audit has produced some positive findings. All New Zealand hospitals now use troponin testing to ascertain whether myocyte necrosis has occurred. In contrast, a recent survey showed that only 70% of Scottish hospitals had access to troponin testing.\textsuperscript{16} New Zealand has also achieved a world first in that the new definition of MI, based on troponin levels, has already been incorporated into our driving guidelines.\textsuperscript{17}

How worthwhile are guidelines? A systematic review of 235 studies\textsuperscript{18} showed that the implementation of guidelines resulted in a 6% relative improvement in care when used as part of a multifaceted approach. Surprisingly, there are few New Zealand data evaluating the impact of guidelines, although several before-and-after observational studies have been published.
In my view, guidelines should be patient-focussed with an emphasis on evidence-based, high-quality treatments. They should also include implementation strategies to ensure equitable access for all New Zealanders, and should be transparent about deficits in funding, resources, and access. They should not, however, be driven by cost-containment or service-rationing, because clinicians are unlikely to use them if these (rather than quality improvement) are perceived to be the real agenda.\textsuperscript{19} Guidelines should take into account the value of clinical experience and judgment, and the importance of doctor- and nurse-patient relationships. To not use cost-effective treatment is morally wrong, and clinicians should not be put in that position.

Adherence to guidelines can only be ensured if users are involved in their development.\textsuperscript{20} The guideline development process should aim for as wide a consensus as possible so that the necessary mechanisms can be quickly put in place to fund and implement the recommendations as soon as possible after publication.

\textbf{Figure 2. The cycle of continuous quality improvement in patient care}  

Despite considerable expenditure on clinical research, little has been done to ensure that research findings are incorporated rapidly into routine clinical practice. We need to close the gap between research and practice. Guidelines are just one stage on the pathway (Figure 2) from basic laboratory research, through large randomised clinical trials with hard clinical endpoints, to definition of performance indicators, measurement of those indicators based on adherence to guidelines—and finally, measurement of patient outcomes.

In New Zealand, we have focussed mainly on the initial part of this cycle, and are now expending vast amounts of energy, expertise and money on the generation of guidelines—but little on systematic assessment of delivery of care through the use of performance indicators and feedback to doctors, nurses, patients, and funders.
Should guideline recommendations be influenced by resource issues, or are resource issues the responsibility of the relevant funding agencies? I believe that guidelines should take into account the benefits, adverse effects and cost-effectiveness of different treatment options, and that it is the Government’s responsibility to provide the necessary resources.

Clinicians in some specialties have lobbied successfully and appropriately for increases in resource allocation to benefit their patients. New Zealand’s current hip replacement rate is 1.4 per 100,000, with major inequities between different centres. Australia’s current rate is 1.9 per 100,000. Thanks to a recent initiative, it is now planned to increase our hip replacement rate to 2.4 per 100,000, which will be 26% higher than in Australia. So it is clear that appropriate funding can be obtained if a good enough case is put on behalf of patients.

In recent times, New Zealand has missed the boat with regard to a number of important developments in cardiology. In the 1980s, we didn’t argue hard enough for all patients (with some exceptions) to have an exercise test—and as a result we still don’t have enough treadmill exercise testing facilities. In the 1990s, we didn’t insist upon echocardiograms for most patients with heart failure or atrial fibrillation—and so now we don’t have adequate echocardiography facilities.

In 2004, we should be lobbying harder for greater access to clopidogrel, glycoprotein IIb/IIIa inhibitors, implantable defibrillators, catheterisation facilities, revascularisation procedures (including coronary artery bypass grafting) and drug-eluting stents.

Carefully articulated arguments are needed to demonstrate the benefits, adverse effects and cost-effectiveness of each treatment option (in comparison with other health initiatives).

**Conclusion**

At present, the management of patients with acute coronary syndromes in New Zealand is neither equitable nor appropriate. Electronic audit methods, with rapid access to data and feedback, should be introduced to provide early warning of changes in the equity and quality of patient care. Implementation of best-practice guidelines would go a long way towards reducing inequities and improving patient care. Measurement of quality indicators and audits of adherence to best-practice guidelines would also encourage good clinical practice. Appropriate resourcing will be needed.

We must not ‘dumb-down’ our expectations of access to new and better treatments and equity of medical care for all New Zealanders. Our country deserves no less.

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Poisoning by wild honey

This extract is taken from an article by Dr E. D. Aubin that was published in the New Zealand Medical Journal 1905, Volume 4 (13), p19–24.

The knowledge of poisoning by wild honey extends into remote antiquity, dating from the time of our old friend Xenophon. Although of not frequent occurrence in modern times, cases have been reported in various parts of the world, such as in India and South America. In New Zealand the victims have mostly been Maoris, and the districts affected Thames, Piako, and the East Coast.

There seems to be some doubt as to the source of the poison. According to Mr. I. Hopkins, Government Apiarist, who has taken a good deal of interest in the subject, the responsibility rests with the yellow flowers of a cress-like plant called the “whauriki,” which grows chiefly in swamps. In other countries a species of Rhododendron has been suspected. In any case, the noxious material is either gathered by the bees directly from the flowers, or is elaborated from the products of the flower, or evolved by decomposition at a later date.

Wild honey only is affected, especially that deposited in or near swamps and in certain parts of the bush. There is no instance, as far as I am aware, of poisoning by cultivated honey.

Discussion

Dr. Eccles said he had a good deal of experience of honey poisoning in the north, and the symptoms generally were such as Dr Aubin had described. He did not think the poisoned honey came from the whauriki, but from another plant in the bush something like a sycamore, the leaf being very white underneath. It flowered rather later than most flowering shrubs. He had, unfortunately, forgotten the name of the plant.

It was noticed that honey poisoning occurred only when that shrub was in flower. It was not generally known that whenever bush honey was found to be poisonous the combs where not sealed, and the Natives in the north would not eat honey unless they saw that the comb was sealed. Almost every case of honey poisoning he had seen had originated from eating honey brought home by the youngsters, and investigation afterwards always proved that the combs had not properly sealed. With regard to treatment, he was a great believer in stimulants. He first of all gave an ordinary emetic and purgative, and then gave stimulants.

Dr. W. Brown said it had been his misfortune to see four and the remains of two other cases of honey poisoning. The four cases which he saw were all in one family, being a mother and her children, ranging in age from eight to twelve years. They all had convulsions, which lasted off and on for about five hours—practically the whole night long—and it was a most alarming state of affairs. He gave them bromide of potassium, which they kept throwing up. The children recovered in a day or two, but the mother was ill for some considerable time.
Note: According to the NZ Food Safety Authority in October 2003, the plant responsible for toxic honey is the tutu (Coriaria arborea), and the last known honey poisoning case was in 1991. See http://www.nzfsa.govt.nz/animalproducts/publications/info-pamphlet/bee-products/toxic-honey.htm
Proceedings of the Scientific Meeting of the Christchurch Medical Research Society, Friday 30 July 2003

Determination of house dust mite numbers and allergen levels in floor coverings: Some practical considerations. C Shorter, SM Causer, KJ Botica; Canesis Networks Ltd, Lincoln, North Canterbury.

In assessing house dust mite numbers and allergen levels (Der p I) on existing carpets in six Christchurch homes, a ‘mobility’ test, which relied on capturing mites on an adhesive film as a result of natural movement, resulted in low mite recoveries (mean 6.6 mites/141 x 141 mm). These were not correlated with those obtained with a ‘heat escape’ method (mean 104 mites/141 x 141 mm) ($r^2 = 0.11$), which uses heat application to increase recovery rates. Because mobility testing is affected by external factors, such as room temperature, it perhaps should be considered more as an indicator of mite activity than total numbers.

Allergen levels measured in core samples were not correlated with mite numbers determined using the heat escape method ($r^2 = 0.044$). No correlation was found between allergen levels in carpet cores (mean 2342.7 µg/m² Der p I) and vacuum samples (mean 576.6 µg/g Der p I) ($r^2 = 0.002$), suggesting that vacuum sampling does not reflect the total amount of allergen contained in the carpet, rather that in the dust fraction able to be dislodged by vacuuming, which is likely influenced by airflow rate, agitation and carpet structure.

Carpet structure also needs to be considered when using the heat escape technique. In a laboratory trial, mite recoveries from loop-pile carpets were significantly lower than those from cut-pile carpets (p>0.05), while recoveries on short-pile carpet (6.5 mm) were also significantly higher than those on long-pile carpets (9 mm) (p>0.05).

We conclude that, where possible, heat escape testing should be used in preference to mobility testing, as it provides a more accurate measure of mite numbers. Likewise, core sampling provides a better measure of total allergen content than vacuum sampling, but ideally, both should be performed.

A novel biomaterial for direct cell and protein patterning: potential applications in tendon and ligament repair. MA Ali$^{1,2}$, W He$^2$, D Greenberg$^2$, KE Gonsalves$^2$; $^1$Biopolymer Research Group, Canesis Networks Ltd, Lincoln, North Canterbury; $^2$Polymer & Nanotechnology Research Laboratory, C. C. Cameron Applied Research Center, University of North Carolina, USA.

A novel biocompatible biomaterial was developed for applications in microlithography. Microlithography is the process of micro- or nano-scale patterning on a surface such as glass, plastic or semiconductor wafer. Microlithography processes are commonly used for the fabrication of micro-/nano devices and chips for electronic applications. In these studies, we used our newly developed biomaterials for the fabrication of micro-/nano- patterned materials and design of bioscaffold biodevices for medical applications such as cartilage and ligament repair.
This novel biomaterial and its bioscaffolds were prepared through copolymerization and/or photopolymerization by incorporating novel initiators and co-diluents. The biomaterials were characterized by NMR, IR and elemental analysis. Micro- to nano-patterning and micro-/nano-biodevice fabrications were performed with this novel biomaterial using photolithographic techniques. After photolithography the newly developed biomaterials have distinct hydrophobic and hydrophilic micro-patterned regions. Using rat fibroblast cell lines, we observed that cell adhesion, proliferation and differentiation were significantly enhanced along the hydrophilic pattern regions.

Thus the biomaterial is a promising candidate for the formation of extra cellular matrix (ECM) in tissue engineering, particularly for tendon and ligament repair. This biocompatible biomaterial can also improve conventional lithography, including applications for micro-stamping techniques commonly use for the fabrication of biosensors, bio-immuno-sensors and biochips. In addition this novel biomaterial potentially has applications in tissue engineering by direct cell and protein patterning because novel functionalities can be introduced through the copolymerization and photopolymerization processes.

Lapses of consciousness during a continuous tracking task. MTR. Peiris1,2,3, RD Jones1,2,3, GJ Carroll1,4, PJ Bones1,3; 1Department of Electrical and Computer Engineering, University of Canterbury, Christchurch; 2Department of Medical Physics and Bioengineering, Christchurch Hospital, Christchurch; 3Van der Veer Institute for Parkinson’s and Brain Research, Christchurch; 4Department of Neurology, Christchurch Hospital, Christchurch. Lapses of consciousness (‘microsleeps’) and falling asleep are considered major causes of serious accidents in the transport sector. Hence, it would be of considerable value if a person could be monitored and any lapses of consciousness (LoCs) detected automatically so that preventative or remedial action can be undertaken to maintain safety. The primary aim of this study was to capture and investigate LoCs.

Fifteen normal non-sleep-deprived male subjects (18–36 years) were observed on two afternoons (7–50 days apart) while performing a continuous tracking task for 1 hour. EEG, eye movements, tracking performance, and video were recorded. Subjects were required to refrain from taking any stimulants/depressants during the 4 hours prior to the sessions. A LoC was defined as a temporary (> 1.0 s) complete loss of responsiveness, indicated by a lapse in tracking performance concurrent with an apparent loss of consciousness as determined independently by video observation.

Eleven of the 15 subjects had a LoC at some stage. Four subjects averaged over 50 LoC/h. The mean rate of lapsing over all subjects was 29.1 LoC/h. The mean duration of a LoC was 4.0 s. Lapses in performance were caused by both LoCs (30.1%) and lapses of attention (69.9%). There was no correlation between age of subject and number of LoCs.

This study indicates that LoCs can occur in young healthy adults to a much greater extent than previously recognized. This has major implications for occupations that require sustained alertness over long periods of time.
An aspirin a day keeps breast cancer away?

A population-based case control study of women with breast cancer (1442 cases and 1420 controls) has shown that taking aspirin seven or more times a week reduces the risk of breast cancer by 28%. The drug reduced the risk of hormone receptive positive tumours but not hormone receptor negative tumours.

It is hypothesized that this effect is achieved by the inhibition of cyclooxygenase2 (COX-2) as the latter has increased gene expression in hormone receptor-positive breast cancers. Ibuprofen consumption produced a weaker effect and paracetamol had no effect.

Accuracy in blood pressure measurement

Although blood pressure is the commonest clinical measurement used in hospitals, consulting rooms and, more recently, homes and workplaces, numerous technical errors are known to influence its accuracy. Most blood pressure audits have focused on device functionality, cuff size and systolic and diastolic blood pressure detection.

In an interesting recent paper two Australian physicians remind us that it has been recognized for almost 100 years that blood pressure increases with arm dependency. Recent research has demonstrated that this artefact is exaggerated the higher the blood pressure. For example, a blood pressure of 155/85 mmHg would increase by 25/11 mmHg to 180/96 mmHg by lowering the arm from the horizontal position to a dependent position, whereas a much smaller absolute increase would occur if the blood pressure was 120/80 mmHg.

They audited the arm position preference of the 182 clinicians in their hospital and found a marked variation. They (and I) recommend that the arm should be horizontal.

Trouble at t’Mill (Hill)?

Scientists at the National Institute for Medical Research (NIMR) at Mill Hill in north London are worried that their institute could soon be split up. The Medical Research Council (MRC) has confirmed that it is revisiting a previous decision to keep the NIMR—one of Britain’s premier centres for basic medical research—on one site.

A task force has since consulted London hospitals and colleges that could potentially offer sites to the new NIMR. “We asked what they could do and they have offered a variety of proposals,” says Colin Blakemore, chief executive of the MRC and chairman of the task force reviewing the institute’s fate. “We would like to keep the NIMR as one institute. But there are practical constraints,” he says. “We have to look at more modest possibilities.”
Publication bias

Methuselah suspects that there are a lot of negative clinical trials that never see the light of day, leading to a bias in favour of published results. Hence I was somewhat surprised to find there are now at least three journals dedicated to the promotion of scientific negatives: The Journal of Negative Results in Biomedicine (www.jnrbm.com/home), the Journal of Negative Observations in Genetic Oncology (www.path.jhu.edu/NOGO), and the Journal of Negative Results – Ecology & Evolutionary Biology (www.jnr-eeb.org).

Unfortunately these journals appear to be rather specialised and of little interest to the average clinician.

New Scientist 12 June 2004, p30

The exception—a negative clinical trial in a prestigious journal

Degeneration of cholinergic basal forebrain neurons innervating the cortex is believed to contribute substantially to cognitive deficits seen in Alzheimer’s disease. This discovery triggered development of cholinesterase inhibitors, which aim to raise acetylcholine levels in the brain by blocking the enzymes that metabolise this molecule. Donepezil was the first such drug to be licensed in the UK, in March 1997, followed by rivastigmine and galantamine.

Researchers in Birmingham conducted a randomised trial comparing donepezil and placebo to determine whether donepezil produces worthwhile improvements in disability, dependency, behavioural and psychological symptoms, carers’ psychological wellbeing, or delay in institutionalisation.

No significant benefits were seen with donepezil compared with placebo in institutionalisation (42% vs 44% at 3 years; p=0.4) or progression of disability (58% vs 59% at 3 years; p=0.4).

Similarly, no significant differences were seen between donepezil and placebo in behavioural and psychological symptoms, carer psychopathology, formal care costs, unpaid caregiver time, adverse events or deaths, or between 5 mg and 10 mg donepezil.

Their conclusion was that donepezil is not cost effective, with benefits below minimally relevant thresholds. More effective treatments than cholinesterase inhibitors are needed for Alzheimer’s disease.

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Complaints against doctors

I have just finished an audit of written complaints made against doctors working at the Lower Hutt After Hours Medical Centre, which is staffed by shareholder GPs and contract doctors. It provides GP-level services after hours and, more recently, has also been open during the day.

There were 27,167 consultations in the year ending 30th June 2004. There were 21 written complaints, at a rate of 0.8/1000 consultations. Of the complaints, 11 could primarily be described as wanting a refund of fees after an illness had not settled as quickly as the complainant would like. Eight other complaints raised concerns regarding medical management, and could be described as more serious in nature.

It was interesting to note that doctors working the overnight shift were 6 times more likely to have a complaint made against them, compared to if they worked the day or evening shifts. They were also 8.5 times more at risk of getting a serious complaint made against them.

In 6 out of 8 of the more serious complaints, doctor manner was mentioned. A dishevelled appearance, lack of introduction, disinterested manner, or perceived rudeness counted against the doctor.

I suspect rates of complaints against doctors working in after hours medical centres are at least 5 times higher than if they were working in their own practice—as the doctor usually does not know the patient. Multiply this by 6 times more if working overnight.

Any perceived shortcomings of the doctor by the patient are less likely to be given the ‘benefit of the doubt’, and a good doctor manner and appearance are important in complaint prevention, especially overnight.

Overall, 99.992% of consultations were not complained about, indicating that overall we are not doing too badly. It would be interesting to know about complaints rates in other After Hours Centres, as I cannot find any information on this in the literature.

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Familial Mediterranean Fever

We read with interest Casey et al’s report on a New Zealand case of Familial Mediterranean Fever (FMF) published recently in the New Zealand Medical Journal (NZMJ). It is increasingly becoming evident that this disease, although only common in Middle East populations, should also be considered in every relevant clinical situation, everywhere in the world. Following cloning of the MEFV gene, it is expected that pyrin, the MEFV-coded protein that is mutated in FMF, will attract major interest in the years to come.

Several independent groups have recently shown that the disease is considerably spread within many populations of the Mediterranean Basin—namely, Greeks, Cypriots, Italians, and Spanish. Some so-called phenotype II FMF cases (renal amyloidosis being the presenting symptom) are also increasingly reported from the same areas. The distribution of pyrin gene mutations is complex among highly affected populations (ie, Arabs-Jewish-Armenians-Turks); that is, a limited number of mutations (less than 5) account for the vast majority of cases—as opposed to populations non-highly affected by the disease where the 5 more common mutations cover less than 70–80% of FMF chromosomes.

In these last populations, many private mutations are encountered—some 50 have been recorded until now. Therefore, non-classically affected populations provide a tool for detecting more MEFV (‘atypical’ / ‘private’) gene mutations. The authors who published their case in the NZMJ are not very clear about the case’s ethnic origin*, although according to their writing it is implied that she does not belong to the aborigine population group. The case proved to be V726A homozygote and her sister carried the same mutation as well; mutation V726A is proportionally common in Cypriots, and also in other populations including Greeks.

In terms of population genetics, it would be interesting if pyrin mutations exist among Oceanian Aborigines. To the best of our knowledge, no FMF cases from this population have been reported so far. Therefore, searching in this population group for MEFV mutations by NZ physicians is strongly encouraged (in clinically relevant cases). Given the pattern of mutations among populations, such testing may reveal more FMF associated mutants. In this context, screening Oceanian populations for MEFV mutations should be a part towards a proposed Human Genetic Diversity Project.

*NZMJ note: As outlined in Casey et al’s paper, the case’s ethnic origin is Ashkenazi Jew.

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References:


John Arthur Reginald Miles

John Miles (CBE) was born in Sidcup, England, in 1913 and received his medical education at Cambridge University and St Thomas’s Hospital, London. After graduation in 1938, he spent several years training in Pathology at St Thomas’s and 5 years (1946–1950) as Huddersfield Lecturer in Special Pathology, University of Cambridge, and completed his MD in 1951.

John accepted a position as Chief of the Medical Research Division, Institute of Medical and Veterinary Science in Adelaide in 1951, before coming to New Zealand in 1955 as the Professor of Microbiology at the University of Otago, a position which he continued to hold with distinction for 23 years.

At the time of John’s arrival at Otago, the name of the department had recently been changed from Bacteriology on the movement of the previous Head, Sir Charles Hercus, to Dean of the Medical School.

John will always be remembered as a medical scientist of great distinction, who continually fostered the links between science and medicine, something unusual back in the mid-1950s. He clearly became the father of microbiology as a scientific tertiary discipline in New Zealand, and was the driving force behind the establishment and subsequent success of the Department of Microbiology (now the Department of Microbiology and Immunology) at the University of Otago—a department presently containing over 50 post-graduate students. John’s prime objective of excellence in research has clearly continued.

John was a Fellow of the Royal Society of Medicine, London, an internationally recognised microbiologist and Consultant for the World Health Organization (WHO), and a member of many research assessing committees and international societies. He was elected a Fellow of the Royal Society of New Zealand in 1962, and served as President from 1966 to 1970. His contributions to academic microbiology and medical research were recognised with the award of the CBE in 1971.

John’s early work in Adelaide involved studies on the cause and epidemiology of Murray Valley encephalitis, and this interest in viruses transmitted to humans by mosquitoes continued after his move to Otago in 1955 and subsequent (1960) appointment as Honorary Director of the MRC Virus Research Unit in Dunedin. Here he set up field studies of arthropod-borne viruses both in New Zealand and in several Pacific Islands.

He was involved with the isolation of Whataroa virus in South Westland, with studies of dengue in Fiji, with respiratory viruses in New Zealand and Fiji, with the massive epidemic of Ross River virus in the Pacific, with hepatitis viruses in New Zealand and
the Pacific, and (not long before retirement) with an expedition to study scrub typhus in the Solomon Islands.

He was instrumental in setting up the Wellcome Virus Laboratory in Suva in the early 1970s. This laboratory was staffed from Dunedin and provided research and routine diagnostic facilities for the region. Through his involvement with WHO, John was able to establish good contacts with laboratories all around the world, and his experience was recognised through his membership of several WHO Expert Committees.

He was an author of 138 scientific publication between 1936 and 1981. His principal leisure activities included ornithology and fishing, while his generosity as a host and passion for rowing and for spaniel dogs will be remembered by many. Another important thread in John’s life was his Anglican faith, and he was actively involved with St Pauls’ Cathedral in Dunedin and more latterly with St Columba Church in Wanaka. He was a life member of the St Martin’s Island community in Dunedin.

After his retirement from the University, John moved permanently to his holiday home at Hawea, although he remained a frequent visitor to Dunedin and the Department. His first wife, Ruth, died in 1980 and his second wife, Vi (nee Miller), died in 2003.

John died at Elmslie House, Wanaka, on January 20, 2004, after a brief illness. He is survived by two daughters from his first marriage.

We are grateful to Professor Sandy (J.M.B.) Smith for this obituary, and we also thank Terry Maguire for supplying the photograph.
ABC of Rheumatology, 3rd edition


Musculoskeletal problems are common in both general and hospital practice. One of the challenges is differentiating the patient with a potentially serious rheumatological condition from the patient with a more benign condition. Furthermore, most practitioners (other than rheumatologists) will have only a handful of patients with more serious rheumatological conditions in their practice. This book provides a concise, up-to-date overview of musculoskeletal presentations and rheumatological conditions formatted in an easy to read manner.

The first chapter provides an outline of rheumatology in the community highlighting the role of specialist nurses. Importantly, it provides excellent summary tables which outline the critical information required in the referral letter, symptoms of early inflammatory disease, and red flags for regional pain syndromes. The initial few chapters then detail regional pain presentations, while the bulk of the book deals with specific conditions.

The layout is clear with plenty of pictures and tables providing key information on disease features, differential diagnosis, investigation, and treatment. The important side effects and toxicity monitoring required for commonly used disease-modifying anti-rheumatic drugs is covered, with the proviso that there is considerable variation among individual rheumatologists.

The role of the newer biological agents, which are currently only available for paediatric patients in New Zealand, are discussed briefly and provide a good introduction to these agents. The chapter on laboratory investigations provides a brief but excellent summary of common abnormalities and auto-antibodies in patients with rheumatological disorders. This book also highlights the importance of the multidisciplinary team approach, including both primary and secondary care centered around the patient.

In summary, this book is an excellent resource for general practitioners involved in the investigation and management of patients with rheumatological conditions. In addition, it is an appropriate resource for both medical students and FRACP candidates.

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**ABC of Sexually Transmitted Infections, 5th edition**


The ABC series published by the BMJ group are primarily aimed at medical students but could be useful to the junior doctor embarking on GP or early speciality training. This 5th edition of the ABC of Sexually Transmitted Infection has been updated, and importantly contains two introductory chapters outlining the importance of sexually transmitted infections worldwide and their control and prevention.

This book is written by UK-based consultants specialising in Genitourinary Medicine and HIV—and as such reflects British practice and treatment regimens. Therefore, students who are based in Australasia should be prepared to check treatment regimens and antibiotic sensitivity data locally, and amend the book to their own needs.

The book is logically laid out with the first chapters dealing with control and prevention. The following chapters then deal with clinical presentation and examination—within these chapters there are very useful overview tables, which compare and contrast sexually transmitted infections with similar presentations, thus aiding the student to establish a diagnosis.

The chapters dealing with the specific illnesses of syphilis, viral hepatitis, and HIV do so in a clear and concise manner—pointing the student toward more detailed texts, which will certainly be needed.

The tables and diagrams within the book are clear and easy to digest, and the clinical pictures are clear and interesting—but the detail in the microbiology slides is poor and the result disappointing. The last chapter in the book dealing with the laboratory diagnosis of sexually transmitted infections is short, and would need augmenting with a basic microbiology text.

In overview, this is an excellent introductory text to sexually transmitted infections that provides a good basic level of information. Any student with an interest in the area will be able to use this text to good effect and then use the references provided to extend their reading.

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