My mother, Whaea, was an articulate professional Māori woman from Te Aupouri, Te Rarawa. She had participated with distinction in team sports at school and regionally. She was also very articulate in both the English and Māori languages, with Māori being her 'default setting'. During her professional career she had been head of the Māori Department at a secondary school for girls in Auckland City and had lectured at St John's Theological College.

She said that she had suffered with a chest infection in her early childhood. And then in her mid- to late-40s she developed a worsening cough. She was a non-smoker and, despite repeated courses of antibiotics from her GP, her cough did not get better. Eventually she had a chest x-ray which was not followed up even though it was abnormal. Only at my insistence did she ask to have further investigation and this resulted in a diagnosis of bronchiectasis. She had bilateral disease; that is, the disease in both lungs. She was in her early 50s and this diagnosis came after three to four years of a worsening and persistent cough.

This diagnosis began a journey of nearly 15 years of repeated hospital admissions, countless courses of oral and intravenous antibiotics, and numerous admissions for physiotherapy. During this time my mother insisted on maintaining her many roles, with these often involving travel and attendance at hui. She knew how unwell she was but would brush off people's comments about her cough, and charm them with her sense of humour.

Whānau continued to be central in her life, with grandchildren staying with her and Dad or going away on trips with them. When she needed to go into hospital for treatment it was almost 'enforced rest', with whānau supporting her all the way.

And then almost overnight she became worse and the hospital stays became longer. She lost appetite and weight and found that she could no longer continue in her work. My Dad looked after her at home and then my sister moved in with them and helped out. My sister was able to help them host whānau and visitors, and to also be strict about when visiting time was over. The whānau also gathered around to make decisions about the ongoing care of both my father and my mother.

Toward the end of her life my mother had very limited mobility and was on continuous oxygen. Her personal care, such as bathing and dressing, was undertaken by her immediate family. And then in 1998, when she was just 66 years of age, my mother died of bronchiectasis in Auckland Greenlane Hospital. She is remembered with love, and greatly missed.

Ramon Pink

# 10 RESPIRATORY DISEASE

*Sue Crengle, Ramon Pink, Suzanne Pitama*[1]

In 2000–2004, respiratory diseases were one of the five leading causes of death and hospitalisation for Māori, with significant inequalities compared with non-Māori. This chapter focuses on two respiratory diseases: bronchiectasis and asthma. The evidence of disparities between Māori and non-Māori is examined using existing evidence as well as data specifically analysed for this edition of *Hauora* (summarised in Table 10.3 at the end of this section along with data on chronic obstructive pulmonary disease (COPD) and pneumonia).

## Bronchiectasis

Bronchiectasis is a chronic respiratory illness contributing to morbidity and mortality disparities between Māori and non-Māori (National Health Committee 1998). The term is derived from the Greek '*bronkos*' meaning bronchial or airway and '*ektasis*' meaning stretching or extension. Bronchiectasis is defined as an abnormal irreversible dilatation of one or more bronchi of the lungs (Cole 1990). It can be regarded as the common outcome of a number of conditions such as unknown (idiopathic) causes or, the most common and important cause, repeated or severe infection of the lung from pneumonia, tuberculosis or whooping cough (Whitwell 1952; Kolbe & Wells 1996).

People with bronchiectasis will typically have a persistent cough with copious amounts of sputum. The cough can be associated with wheeze and blood in the sputum. The cough tends to be worse in the mornings and is often brought on by changes in posture.

The mainstay of the management of bronchiectasis is antibiotic therapy and regular postural drainage.[2] Antibiotics are used for acute exacerbations, with some patients requiring long term treatment. Yearly influenza vaccinations and 5 to 10-yearly pneumococcal vaccinations are also important for the management of bronchiectasis. Infant vaccination against diseases such as whooping cough and the timely treatment of acute chest infection is crucial in preventing bronchiectasis from occurring. Surgical removal of affected lung occurs rarely. There are varying degrees of severity of the disease and prognosis is poorly understood (Keistinen et al 1997).

### Prevalence and inequalities

Bronchiectasis is a disease more commonly found in developing and underdeveloped nations that lack access to antibiotics, vaccination, and diagnostic technology. The prevalence of bronchiectasis is difficult to estimate as diagnosis is usually made by radiological investigation, but has been estimated at 1.3 per 1,000 in developed

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1 The authors are listed here in alphabetical order. Sue Crengle wrote the asthma section. Ramon Pink and Suzanne Pitama authored the bronchiectasis section

2 Postural drainage refers to the bringing up of excess sputum by lying in various prone positions while firmly patting the chest, thereby loosening secretions, particularly from the base of the lungs

countries (Cole 1990). However, bronchiectasis remains a serious health issue in the indigenous populations of New Zealand, the United States, and Australia (Edwards et al 2002; Singleton et al 2000; Chang et al 2002).

Almost half a century ago a study of patients at the Auckland Greenlane Hospital Chest Unit showed that the proportion of Māori patients admitted to hospital suffering from bronchiectasis was considerably higher than the non-Māori group (Hinds 1958). More recent evidence at both Paediatric and Adult Chest Clinics in Auckland show that Māori and Pacific peoples continue to be affected by bronchiectasis significantly more than non-Māori and non-Pacific in the Auckland region (Edwards et al 2002; Kolbe & Wells 1996).

Māori and Pacific children with bronchiectasis experienced more socioeconomic deprivation and had lower immunisation rates. In an Auckland based paediatric study the estimated prevalence of bronchiectasis was approximately 1 per 6,000 and was found to be more common in Pacific and Māori children (Edwards et al 2003). In a cross-sectional survey of patients admitted to Greenlane Hospital Respiratory Service in 1992/1993 with acute infective exacerbation of bronchiectasis, Māori and Pacific peoples were markedly over represented (Kolbe and Wells 1996). The authors concluded that their results indicated the likelihood of a much higher prevalence of bronchiectasis in Māori and Pacific peoples.

Some researchers have suggested that Primary Ciliary Dyskinesia[3] causing bronchiectasis among Māori may have a genetic origin (Wakefield and Waite 1980). However, there is no strong evidence for this and more recently it has been suggested that cilia abnormalities found in Māori with bronchiectasis may well be the result of chronic infection (Kolbe and Wells 1996).

Ethnic inequalities have also been identified in the United States of America, with the prevalence in Alaskan Native American peoples being higher than any other populations of children in the United States (Singleton et al 2000). Socioeconomic disadvantage including poverty, substandard housing, malnutrition, barriers to medical care, and inadequate education, are all likely to have a major impact on the prevalence and outcome of bronchiectasis (Kolbe and Wells 1996; Edwards et al 2003).

Table 10.1 shows the marked disparity between Māori and non-Māori hospitalisation rates for bronchiectasis during the years 2003–2005. Age-sex-standardised rates were 3.6 times higher for Māori than non-Māori. Rates for Māori children were twice those for non-Māori children. The inequalities in hospital admissions tended to increase with age, with Māori rates nearly 6 times higher than non-Māori rates at ages 45–64 years.

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[3] Primary Ciliary Dyskinesia (PCD), also known as Immotile Cilia Syndrome, is a rare genetic birth defect where patients have abnormal or absent ciliary motion. Cilia are tiny hair-like structures that move mucus out of the bronchi. During infections more mucus is produced and because the abnormal cilia can't move, or move ineffectively, mucus becomes stuck and blocks the airways, causing complications. Bronchiectasis is one of those complications. The only definitive way to diagnose PCD is with a biopsy.

**Table 10.1: Bronchiectasis hospitalisations, 2003–2005**

| Age group | Māori | Non-Māori | Rate ratio (95% CI) |
|---|---|---|---|
| | Rate (95% CI) | Rate (95% CI) | |
| All ages | 41.7 (38.8-44.8) | 11.6 (10.5-12.8) | 3.60 (3.19-4.08) |
| 0-14 years | 29.1 (25.2-33.7) | 14.2 (11.8-17.0) | 2.05 (1.62-2.59) |
| 15–24 years | 17.1 (13.1-22.3) | 3.6 (2.2-5.9) | 4.76 (2.70-8.38) |
| 25–44 years | 28.4 (24.1-33.5) | 5.8 (4,5-7.5) | 4.89 (3.63-6.60) |
| 45–64 years | 102.4 (90.6-115.6) | 17.3 (15.0-19.9) | 5.91 (4.91-7.13) |
| 65+ years | 187.8 (157.0-224.7) | 54.1 (49.3-59.5) | 3.47 (2.83-4.25) |

Notes: Rates are calculated per 100,000; rates for 'all ages' and ages 65 years and over were age-sex-standardised to the 2001 Māori population.

Table 10.2 reflects the disparity in mortality from bronchiectasis between Māori and non-Māori and shows that mortality rates from bronchiectasis are 5 to 11 times higher for Māori than for non-Māori. Disparities in mortality rates appear to be disproportionately higher than disparities in hospitalisation rates for bronchiectasis.

**Table 10.2: Bronchiectasis mortality rates, 2000–2004**

| Age group | Māori | Non-Māori | Rate ratio (95% CI) |
|---|---|---|---|
| | Rate (95% CI) | Rate (95% CI) | |
| All ages | 2.1 (1.6–2.7) | 0.3 (0.3–0.4) | 6.70 (4.88–9.21) |
| 15–24 years | 0.2 (0.0–1.3) | | |
| 25–44 years | 1.6 (1.0–2.8) | 0.1 (0.1–0.3) | 11.57 (4.67–28.66) |
| 45–64 years | 4.6 (3.0–7.3) | 0.6 (0.4–1.0) | 7.17 (3.97–12.95) |
| 65+ years | 28.0 (19.5–40.2) | 5.0 (4.2–6.0) | 5.63 (3.76–8.44) |

Notes: Rates are calculated per 100,000; rates for 'all ages' and ages 65 years and over were age-sex-standardised to the 2001 Māori population.

## Addressing prevention, diagnosis, and treatment disparities for bronchiectasis

Māori are disproportionately affected by bronchiectasis. Risk factors for bronchiectasis include early (young age) and repeated chest infections, and low socioeconomic status. Some chest infections, such as pneumonia, tuberculosis, and whooping cough, are the most common events preceding the establishment of bronchiectasis in patients. Therefore, infant vaccinations and the timely use of antibiotics for chest infections are important, particularly in infancy and childhood. High rates of socioeconomic deprivation for Māori are likely to result in reduced access to health care, in particular to antibiotics for acute chest infection. Māori are also significantly less likely to be immunised at age two years (69%) than European/Other children (80%) (Ministry of Health 2006). Targeted support to increase immunisation rates are a critical element in reducing the incidence of diseases contributing to the development of bronchiectasis.

In addition, interviews with clinicians have indicated a low index of suspicion for bronchiectasis amongst primary care and even secondary care physicians (Pink 2004). Bronchiectasis needs to be excluded when Māori with less access to socioeconomic resources present with significant respiratory infection or repeated chest infection. It is imperative that Māori be able to access a high performing health service that provides

timely immunisation to all populations, early diagnosis of the conditions that cause bronchiectasisis, and effective management strategies.

## Asthma

Asthma is a respiratory problem caused by reversible narrowing of the airways. The narrowing is caused by tightening of the muscle in the wall of the airway, inflammation and swelling of the mucosa (lining) of the airways, and excess production of mucus within the airways. The narrowing of the airways and excess mucus production result in a range of symptoms including wheezing, cough, and shortness of breath. In addition to these symptoms, signs of difficulty breathing may be seen.

Although the symptoms and signs of asthma are shared by everyone with asthma, a small proportion of people only experience asthma symptoms when exercising ('exercise-induced asthma'), while in other people asthma is strongly associated with allergies (atopy). The 'course' of asthma also varies from person to person. Some children 'grow out' of asthma as they get older while others will have asthma their whole life, and some people will develop asthma at a later age.

Acute asthma is an episode where there is sudden worsening of asthma symptoms. The severity of acute asthma can vary from mild to life-threatening. Chronic asthma occurs when asthma symptoms occur without an asthma attack. Chronic asthma symptoms may occur occasionally (intermittent chronic asthma) or continuously (chronic persistent asthma).

In 1991 *He Mate Huangō: Māori Asthma Review* reported the findings of a comprehensive inquiry about asthma among Māori people (Pōmare et al 1991). The review was commissioned by the then Minister of Māori Affairs, Hon. Koro Wetere, because of rising concerns about the number of Māori who died or were admitted to hospital for asthma. The review team concluded that improving outcomes from asthma among Māori required activities in a range of areas including:

- involving Māori in the planning and delivery of asthma services
- improved access to care ('mainstream' services, marae-based (or similar) services, Māori asthma workforce development)
- increased education about all aspects of asthma and its management, with information provided in ways that are appropriate, acceptable and effective for Māori
- improved cultural safety among the non-Māori workforce involved in asthma education and/or management
- ongoing research into Māori asthma, including the development and evaluation of new service delivery programmes
- reduction of smoking in Māori communities; and
- the availability of user-friendly asthma action plans for the Māori community.

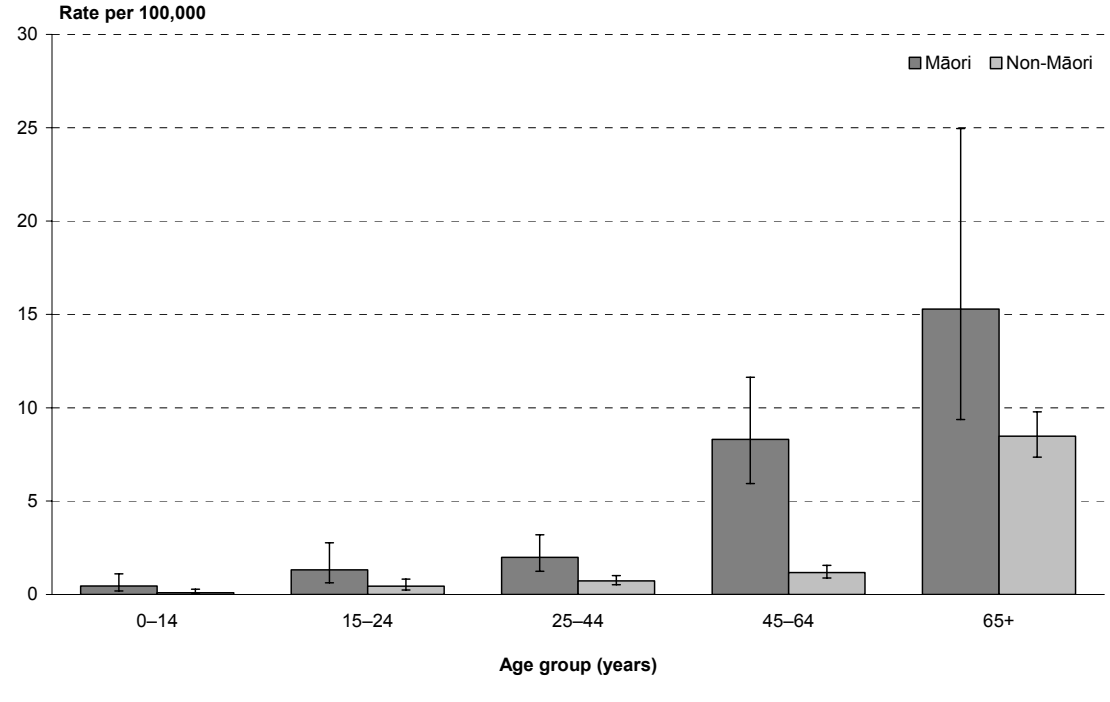
This section provides an update and brief overview of asthma among Māori and disparities in asthma care, along with recommendations for health service providers.

## Māori asthma prevalence and health outcomes

Asthma can affect people of any age, but is more common in children than adults. About 25% of 6–7 year olds and 30% of 13–14 year olds experience asthma symptoms in a 12 month period (Asher et al 2001). Studies have shown the prevalence of asthma symptoms in Māori children is about the same (Barry et al 1991; Moyes et al 1995) or slightly higher (Pattemore et al 1989; Pattemore et al 2004) than that in non-Māori children.

Deaths from asthma are relatively uncommon. Māori and non-Māori death rates in specific age groups are shown in Figure 10.1. In both the Māori and non-Māori populations the asthma mortality rates increase with age and the highest mortality rates are seen in people aged 65 years and over. Māori mortality rates are significantly higher than non-Māori rates in the four age groups from 15 years onwards. There were very few deaths from asthma in children under 15 years of age. The higher mortality rates in people over 45 years of age may, in part, be explained by misclassification, with deaths from COPD being attributed to asthma.

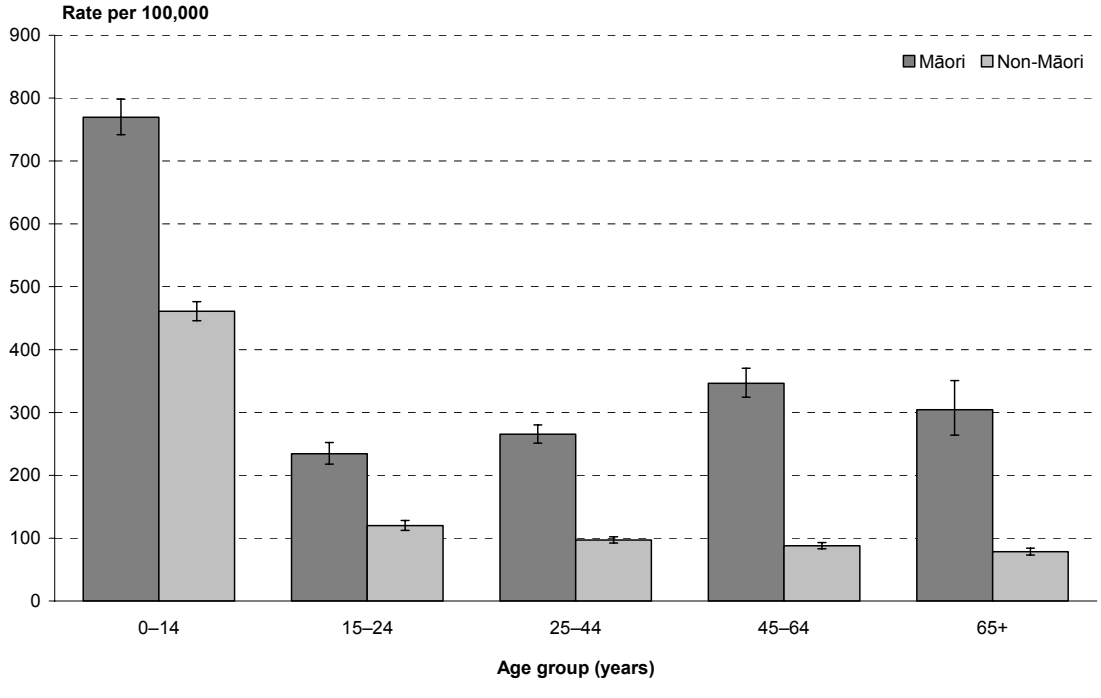
**Figure 10.1: Age-specific asthma death rates, 2000–2004**




Although most people with asthma are successfully cared for in the community, some people require hospitalisation for asthma management. Māori and non-Māori hospitalisation rates for specific age groups during 2003–2005 are shown in Figure 10.2. Hospitalisation rates are highest in the 0–14 year age group for both ethnic groups. In all age groups, Māori hospitalisation rates are higher than non-Māori. These disparities in hospitalisation rates have been documented for many years (Mitchell and Cutler 1984; Mitchell 1991; Ellison-Loschman et al 2004). Any observed differences in the

prevalence of asthma between Māori and non-Māori are relatively small and do not explain the more marked difference in hospitalisation rates. This suggests that ethnic differences in the management and control of asthma in the community may be an important factor in the disparities in hospitalisation rates.

**Figure 10.2: Age-specific asthma hospital discharge rates, 2003–2005**




## Ethnic disparities in asthma management

Most asthma is managed at home by the person with asthma (or their parent/ caregiver), and in the primary care (general practice) setting (Kljakovic and Salmond 1996). Evidence-based guidelines for the diagnosis and management of asthma are available for both adults (New Zealand Guidelines Group 2002) and children (Paediatric Society of New Zealand 2005). Both can be accessed via the New Zealand Guidelines Group website (www.nzgg.org.nz).

There are two main areas in asthma management:

- asthma education, self-management (by the person with asthma, or by the care-givers of children with asthma), and action plans; and
- management with medication.

Asthma education and information about asthma should be given to everyone with asthma. This should be reviewed with the patient, and updated regularly. All adults (over 16 years) and all children who need preventer medication to control their asthma should have a written self-management (action) plan (New Zealand Guidelines Group 2002; Paediatric Society of New Zealand 2005). The management of asthma with medications varies according to the type (acute or chronic) and the severity (mild, moderate, severe, life-threatening) of asthma, and the age of the person with asthma. Medications can be used to treat the symptoms of asthma when they occur ('treater medication') or to prevent asthma occurring ('preventer medication'). Everyone who

uses medications to control and prevent asthma should have their medications reviewed regularly.

Since the late 1980s a number of studies have documented ethnic differences in aspects of asthma management including:

- Asthma education, knowledge, and self-management
  - A trial of a community-based asthma education clinic reported greater improvements in asthma knowledge among European participants than Māori or Pacific participants (Garrett et al 1994).
  - Garrett et al (1989) reported that Māori and Pacific participants in their 1989 study were significantly less likely to have a PEFR (peak expiratory flow rate) meter, and Pacific people were less likely to have an action plan than New Zealand European participants. Garrett et al (1994) also reported that significantly lower proportions of Pacific and Māori participants had a PEFR meter when they were enrolled into the community-based asthma education clinic randomised control trial.
- Medication
  - Some studies have found that fewer Māori and/or Pacific peoples were taking medication ('treater' and/or 'preventer' medicines) than European people (Mitchell and Quested 1988; Mitchell 1991).

These studies have not been able to identify the cause(s) of these disparities because they have not looked at all the factors that might contribute to the disparities.

A more recent study was undertaken in 1999–2001 with a community-based sample of children aged 2–14 years. This study found significant differences in the provision of asthma education, parental asthma knowledge, and medication between Māori and/or Pacific children compared with European/Other children, even when the effects of a wide range of factors that potentially affect asthma management were taken into account. The results strongly suggest that there are ethnic differences in the quality of primary care received by children with asthma (Crengle 2005).

### An asthma management programme designed to improve asthma in the Māori community

After the Māori asthma review (Pōmare et al 1991) a trial of a credit card sized asthma action plan was undertaken with Māori from Wairarapa. Over a six month period, Māori with asthma were seen at marae-based asthma clinics, participated in asthma education, and were provided with asthma action plans. Information about medication use, asthma symptoms and its effect on daily life, and doctor and hospital use was collected. The initial results showed a successful partnership between the community and university researchers, a high participation rate by Māori with asthma, a high level of use of the action plan, and a significant improvement in asthma control (Beasley et al 1993).

Further information on asthma morbidity, health service use, and self-management of asthma was collected two and six years after the programme ended. At follow-up

fewer people had severe asthma morbidity and emergency use of health services (especially emergency GP visits) remained lower than that seen before the programme. However, the percentage of nights woken due to asthma and the proportion of participants taking prescribed regular inhaled steroids had decreased to the levels seen before the programme. The researchers concluded that there were on-going benefits from the programme six years later, but the reinforcement of self-management skills was necessary to maintain the benefits that were initially seen. They also noted the importance of on-going prescription and use of inhaled steroid (preventer) medications (D'Souza et al 2000).

The six-year follow-up also found that the programme had other benefits, in particular cultural affirmation, improved access to other health services, a greater sense of control for participants, and positive impacts on the extended family (Ratima et al 1999).

### What should healthcare providers do to reduce the burden of asthma for Māori?

Health professionals and health services that deliver services to people with asthma have a very important role in the delivery of high quality, effective asthma care. To achieve this, health professionals and services should:

- Ensure their own knowledge of asthma and clinical practice is up-to-date and consistent with the current, evidence-based guidelines.
- Ensure that ethnicity data in patient records is complete, accurate, and collected and used in accordance with the Ministry of Health's ethnicity data protocols.
- Regularly undertake clinical audits to determine the consistency of the care they have delivered with current, evidence-based guidelines, and to identify disparities in care between Māori, Pacific, and European/Other ethnic groups. Strategies to improve asthma care and reduce ethnic disparities should be developed, implemented, and assessed by a follow-up clinical audit.
- Be aware of, and refer people to, the asthma services such as asthma educators and non-governmental organisations (e.g., Asthma Society/Foundation) that are available in their area. Māori health providers that have asthma programmes or Māori staff in 'mainstream' asthma services should be offered to Māori patients.
- Primary health organisations and other services should consider developing and implementing asthma information and asthma management programmes that will improve access to asthma care and the quality of asthma care they deliver, and will reduce the effects of poorly controlled asthma on patients and their whānau.

## Conclusion

Bronchiectasis and asthma continue to be significant health issues for many Māori along with other respiratory diseases such as COPD and pneumonia. Recent research continues to show disparities in prevention strategies, diagnosis and care between Māori and non-Māori for respiratory diseases. Research in the context of asthma also

demonstrates that appropriately designed and delivered health programmes improve Māori health outcomes.

**Table 10.3: Respiratory disease deaths (2000–2004) and public hospital discharges (2003–2005)**

| | | Māori | | Non-Māori | | Rate ratio (95% CI) |
|---|---|---|---|---|---|---|
| | | Number | Rate | Number | Rate | |
| **Respiratory diseases** | | | | | | |
| Total | Deaths | 1,037 | 33.8 | 10,658 | 13.1 | 2.59 (2.42–2.76) |
| | Hospitalisations | 42,182 | 2,249.8 | 138,034 | 1,367.2 | 1.65 (1.62–1.68) |
| Females | Deaths | 546 | 32.5 | 5,234 | 10.6 | 3.06 (2.79–3.36) |
| | Hospitalisations | 20,967 | 2,204.7 | 66,250 | 1,263.7 | 1.74 (1.70–1.79) |
| Males | Deaths | 491 | 35.2 | 5,424 | 15.6 | 2.26 (2.06–2.48) |
| | Hospitalisations | 21,215 | 2,294.9 | 71,784 | 1,470.7 | 1.56 (1.52–1.60) |
| **Chronic obstructive pulmonary disease** | | | | | | |
| Total | Deaths | 759 | 24.7 | 7,453 | 9.3 | 2.65 (2.45–2.86) |
| | Hospitalisations | 5,331 | 261.1 | 25,791 | 73.7 | 3.54 (3.42–3.67) |
| Females | Deaths | 403 | 23.9 | 3,323 | 7.2 | 3.31 (2.98–3.69) |
| | Hospitalisations | 3,167 | 293.1 | 12,413 | 69.6 | 4.21 (4.01–4.42) |
| Males | Deaths | 356 | 25.5 | 4,130 | 11.5 | 2.23 (2.00–2.48) |
| | Hospitalisations | 2,164 | 229.0 | 13,378 | 77.8 | 2.94 (2.80–3.10) |
| **Pneumonia** | | | | | | |
| Total | Deaths | 98 | 3.3 | 1,940 | 1.8 | 1.86 (1.50–2.31) |
| | Hospitalisations | 6,934 | 366.5 | 28,640 | 222.0 | 1.65 (1.59–1.71) |
| Females | Deaths | 45 | 2.6 | 1,233 | 1.7 | 1.60 (1.16–2.20) |
| | Hospitalisations | 3,397 | 351.2 | 13,517 | 203.4 | 1.73 (1.64–1.82) |
| Males | Deaths | 53 | 3.9 | 707 | 1.9 | 2.09 (1.56–2.80) |
| | Hospitalisations | 3,537 | 381.9 | 15,123 | 240.5 | 1.59 (1.51–1.66) |
| **Asthma** | | | | | | |
| Total | Deaths | 79 | 2.6 | 286 | 0.6 | 4.10 (3.12–5.40) |
| | Hospitalisations | 8,459 | 457.3 | 17,054 | 245.2 | 1.86 (1.80–1.93) |
| Females | Deaths | 49 | 3.0 | 188 | 0.7 | 4.43 (3.12–6.29) |
| | Hospitalisations | 4,408 | 474.0 | 9,120 | 235.7 | 2.01 (1.92–2.11) |
| Males | Deaths | 30 | 2.1 | 98 | 0.6 | 3.70 (2.39–5.74) |
| | Hospitalisations | 4,052 | 440.5 | 7,933 | 254.8 | 1.73 (1.64–1.82) |
| **Bronchiectasis** | | | | | | |
| Total | Deaths | 64 | 2.1 | 193 | 0.3 | 6.70 (4.88–9.21) |
| | Hospitalisations | 812 | 41.7 | 1,722 | 11.6 | 3.60 (3.19–4.08) |
| Females | Deaths | 31 | 1.8 | 123 | 0.3 | 5.85 (3.84–8.91) |
| | Hospitalisations | 431 | 42.7 | 1,146 | 13.5 | 3.16 (2.69–3.70) |
| Males | Deaths | 33 | 2.3 | 70 | 0.3 | 7.59 (4.72–12.19) |
| | Hospitalisations | 380 | 40.7 | 577 | 9.6 | 4.23 (3.48–5.16) |

Note: Rates are calculated per 100,000 and were age-standardised to the 2001 Māori population.

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