

HE MATE HUANGO

MAORI ASTHMA REVIEW



He mate huango

MAORI ASTHMA REVIEW

*Report to
the Minister of Maori Affairs
from the review team
to consider asthma among
Maori people*

Review team: Professor Eru Pomare (convenor), Hohua Tutengaehe, Irihapeti Ramsden, Makere Hight, Neil Pearce, Vera Ormsby

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Te Tira Ahu Iwi

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He mihi nui ki a koutou katoa.

He mihi

E te hua o ngo!
E te ngenge haukore
I ahu mai koe i fea?
I ahu mai koe i tafiti?
Ahaha!
I ahu ke mai koe, i nga taurekareka o te ao!
Na te maku koe?
Na te matao koe?
No nga Reporoa koe?
Hi! Aue ngo! Nge!! Nge!! Nge!!
Ara tu! Ara te! Ara ta! Ara tau!!
Rire!! Rire!! Hauroa!!!

E mihi ana ki te matuanui mo ana taonga katoa.
E mihi ana ki te faea, i fakamamaetia ai ia, ki te mamae o te wahine i fanau mai ai, te kaifakaora o te ao i a ia.
E mihi ana ki te tama-o-te-rangimarie, i heke iho ai ia i tona taumata i te rangi ki te fenua.
E mihi ana ki te wairuatapu, te kaifakapumau i nga tumanako o te tangata.
Ka mihi ki nga toi o nga rangi.
Ka mihi ki te fenua toitu.
Ka mihi ki nga hunga kua ngaro i te ao nei,
Ka mihi ki nga hunga ora, ki o ratou farekorero.
Ka mihi ki nga maungatapu.
Ka mihi ki nga waifakatauki.

Ka mihi ki nga marae patuwatawata.

Ka mihi ki nga iwi katoa.

Ka mihi tonu ra ki a Eru Pomare, tumuaki o tenei tira, ona tuahine,
me ona hoa tohunga Pakeha i tautoko ai i tenei kaupapa.

Heoi ano

Kia piki te ora ki a tatou katoa.

Hohua Tutengaehe



Kirihaehae Marae – October 1990

Foreword

Tena koutou katoa

This report comes at a time of great change in both the way our health services are managed and the way we manage asthma. It has always been a puzzle as to why the mortality and morbidity from asthma should be so much greater in Maori people. There has been a growing realisation however that Maori and non-Maori people are not receiving equivalent access to health services. These differences in access occur not only for economic reasons but also for complex cultural reasons which are not always understood by those who are responsible for the organisation and delivery of health services.

These concerns have been particularly great in the field of asthma because asthma seems to be more severe in Maori people. In particular, hospital admissions and, until recently, death rates from asthma have been several times higher for Maori than Pakeha.

This report documents these differences, including marked differences in access to health services and discusses the reasons for their occurrence. In addition, it discusses some recent Maori health initiatives which point the way towards future solutions to the problem of unequal access. Considerable progress has been made in some areas in the development of marae-based health services and health education. However, such initiatives can only be more successful when they involve significant Maori management and are fully integrated with the community they serve. This report builds on previous experience and proposes the development of this approach for asthma treatment and asthma education in the Maori community.

It is important that in addition to marae-based initiatives, all areas of the health service become more sensitive to the needs and aspirations of Maori people. A truly bicultural perspective will contribute towards the elimination of the existing differences in health status

between Maori and non-Maori. This is the interest of all New Zealanders and there is much which non-Maori can learn from recent Maori health initiatives in asthma and other fields.

The Department of Maori Affairs and the Department of Health have supported and encouraged the production of this report. It is hoped that despite current financial constraints, appropriate funding will be forthcoming for addressing the serious problems of asthma in Maori people.

Heoi ano

A handwritten signature in black ink, appearing to read 'Eru W Pomare', with a horizontal line underneath it.

Eru W Pomare
Dean and Professor of Medicine
Wellington School of Medicine

Introduction

Asthma is a major health problem in New Zealand and death rates have been the highest in the world since the 1960s. In the document *Health Goals and Targets for the Year 2000*, recently published by the Department of Health, asthma was ranked among the top 10 New Zealand health problems requiring urgent action to reduce disability and death.

There has been considerable concern at the excessive number of deaths from asthma in Maori people and the large numbers requiring hospital treatment. Although asthma does not appear to be more common among Maori children than Pakeha, it seems to be more severe. Hospital admissions and, until recently, death rates from asthma have been several times higher for Maori.

These concerns about asthma in Maori people have occurred in the context of wider issues about asthma and Maori health in general.

In the past few decades, New Zealand has experienced two epidemics of asthma deaths which have been linked to the introduction and widespread use of two particular asthma drugs.

More generally, despite increasing use of expensive modern medicines since the 1940s, asthma deaths and hospital admissions have not declined. In fact, the death and admission rates have been growing since modern treatment was introduced. As a result, the use of some modern asthma medicines is now being reassessed. In addition, it has been increasingly recognised that the key person in the long-term management of asthma is the informed patient. More emphasis is therefore being given to self-management of asthma, and to asthma education involving consumer participation.

There has also been considerable concern about Maori health in the past few decades. Serious social, economic and cultural inequalities still exist between Maori and non-Maori and are important reasons

for the disproportionately high levels of sickness in Maori people. Accordingly, there has been increasing interest in the Maori concept of health, which emphasises health promotion and disease prevention. There has also been a strong will within the Maori community to become more involved in both the planning and delivery of health care. In particular, there have been a number of marae-based health initiatives, based as much on traditional Maori values as on modern health education.

Explanations for the differences in asthma severity between Maori and Pakeha have generally focused on the management of the asthma itself. In particular, it has been suggested that asthma may be more severe or life-threatening in Maori people because of inadequate management and inadequate access to appropriate health care and asthma education. This in turn stresses the need for greater Maori participation in the planning and delivery of asthma services, and in asthma education.

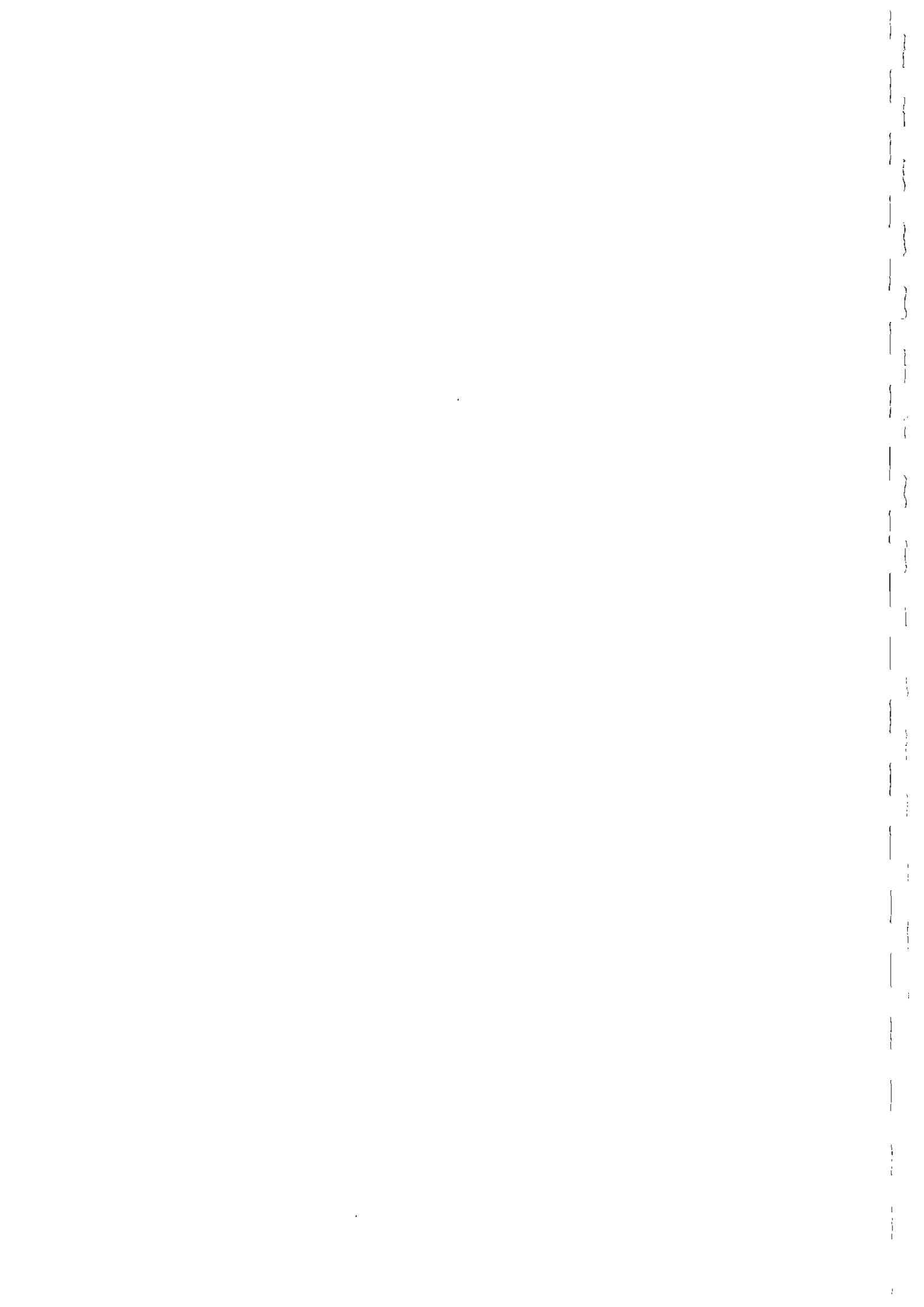
These are serious issues which were made public by the Asthma Foundation of New Zealand during Asthma Awareness Week in 1989. They were brought to the attention of the then Minister of Maori Affairs, the Hon Koro Wetere. As a result, a review team was set up to examine the systems which are in place for finding and helping Maori asthma sufferers.

The team was asked to advise the Minister of Maori Affairs on:

- how many Maori sufferers there are;
- what specialist services are available for them;
- what obstacles prevent Maori people from using these services effectively; and
- the consequences of asthma in the Maori community.

These issues are addressed in this report, which is divided into four main sections. Section 1 discusses general issues of Maori health, including the Treaty of Waitangi, Maori concepts of health, and the classification of ethnicity. Section 2 reviews current knowledge of the prevalence, causes and management of asthma in Maori and non-Maori New Zealanders. Section 3 discusses asthma in Maori people, including problems of access to appropriate health care and asthma education. Section 4 describes the review process. This is followed by recommendations for action.

The report issues a strong challenge to Maori and non-Maori alike. It recommends that there be substantial improvements in asthma management and asthma education, with the significant involvement of Maori people. It is hoped that the report will be read and discussed widely, not only within the Maori community and among those interested in asthma, but also by others interested in creating an environment in New Zealand which fosters the highest levels of health for all.



SECTION 1

Hauora Maori

Maori health



Te Ore Ore Marae – November 1991

CHAPTER 1

Maori health

*We want people to tell us
about asthma – our way.*
Maraeroa – 8 October 1991

Treaty of Waitangi: Maori version

Ko Wikitoria, te Kuini o Ingarani, i tana mahara atawai ki nga Rangatira me nga Hapu o Nu Tirani, i tana hiahia hoki kia tohungia ki a ratou o ratou rangatiratanga, me to ratou wenua, a kia mau tonu hoki te Rongo ki a ratou me te ata noho hoki, kua wakaaro ia he mea tika kia tukua mai tetahi Rangatira hei kai wakarite ki nga tangata maori o Nu Tirani. Kia wakaaetia e nga Rangatira maori te Kawanatanga o te Kuini, ki nga wahi katoa o te wenua nei me nga motu. Na te mea hoki he tokomaha ke nga tangata o tona iwi kua noho ki tenei wenua, a e haere mai nei.

Na, ko te Kuini e hiahia ana kia wakaritea te Kawanatanga kia kaua ai nga kino e puta mai ki te tangata maori ki te pakeha e noho ture kore ana.

Na, kua pai te Kuini kia tukua a hau, a Wiremu Hopihona, he Kapitana i te Roiara Nawi, hei Kawana mo nga wahi katoa o Nu Tirani, e tukua aianeia amua atu ki te Kuini, e mea atu ana ia ki nga Rangatira o te Wakaminenga o nga hapu o Nu Tirani, me era Rangatira atu, enei ture ka korerotia nei.

Ko Te Tuatahi

Ko nga Rangatira o te Wakaminenga me nga Rangatira katoa hoki, kihai i uru ki taua Wakaminenga, ka tuku rawa atu ki te Kuini o Ingarani ake tonu atu te Kawanatanga katoa o o ratou wenua.

Ko Te Tuarua

Ko te Kuini o Ingarani ka wakarite ka wakaae ki nga Rangatira, ki nga hapu, ki nga tangata katoa o Nu Tirani te tino rangatiratanga o o ratou wenua o ratou kainga me o ratou taonga katoa. Otiia ko nga Rangatira o te Wakaminenga me nga Rangatira katōa atu ka tuku ki te Kuini te hokonga o era wahi wenua e pai ai te tangata nona te Wenua, ki te ritenga o te utu e wakaritea ai e ratou ko te kai hoko e meatia nei e te Kuini hei kai hoko mona.

Ko Te Tuatoru

Hei wakaritenga mai hoki tenei mo te wakaetanga ki te Kawanatanga o te Kuini. Ka tiakina e te Kuini o Ingarani nga tangata maori katoa o Nu Tirani. Ka tukua ki a ratou nga tikanga katoa rite tahi ki ana mea ki nga tangata o Ingarani.

(Signed) William Hobson
Consul and Lieutenant-Governor

Na, ko matou, ko nga Rangatira o te Wakaminenga o nga hapu o Nu Tirani, ka huihui nei ki Waitangi. Ko matou hoki ko nga Rangatira o Nu Tirani ka kite nei i te ritenga o enei kupu, ka tangohia, ka wakaetia katoatia e matou. Koia ka tohungia ai o matou ingoa o matou tohu. Ka meatia tenei ki Waitangi i te ono o nga ra o Pepuere, i te tau kotahi mano, e waru rau ewa tekau o to tatou Ariki.

Ko nga Rangatira o te Wakaminenga

Treaty of Waitangi: English translation of Maori version
(Professor Sir Hugh Kawharu)

Victoria, The Queen of England, in her concern to protect the chiefs and subtribes of New Zealand and in her desire to preserve their chieftainship and their lands to them and to maintain peace and good order considers it just to appoint an administrator one who will negotiate with the people of New Zealand to the end that their chiefs will agree to the Queen's Government being established over all parts of this land and (adjoining) islands and also because there are many of her subjects already living on this land and others yet to come.

So the Queen desires to establish a government so that no evil will come to Maori and European living in a state of lawlessness.

So the Queen has appointed me, William Hobson a captain in the Royal Navy to be Governor for all parts of New Zealand (both those) shortly to be received by the Queen and (those) to be received thereafter and presents to the chiefs of the Confederation chiefs of the subtribes of New Zealand and other chiefs these laws set out here.

The First

The Chiefs of the Confederation and all the chiefs who have not joined that Confederation give absolutely to the Queen of England for ever the complete government over their land.

The Second

The Queen of England agrees to protect the Chiefs, the subtribes and all the people of New Zealand in the unqualified exercise of their chieftainship over their lands, villages and all their treasures. But on the other hand the Chiefs of the Confederation and all the Chiefs will sell land to the Queen at a price agreed to by the person owning it and by the person buying it (the latter being) appointed by the Queen as her purchase agent.

The Third

For this agreed arrangement therefore concerning the Government of the Queen, the Queen of England will protect all the ordinary people of New Zealand and will give them the same rights and duties of citizenship as the people of England.

*(Signed) William Hobson
Consul and Lieutenant-Governor*

So we, the Chiefs of the Confederation and the subtribes of New Zealand meeting here at Waitangi having seen the shape of these words which we accept and agree to record our names and marks thus. Was done at Waitangi on the sixth of February in the year of our Lord 1840.

The Chiefs of the Confederation

Implications of the Treaty of Waitangi

The implications of the Treaty of Waitangi for health and for health authorities have been the subject of various documents from the Department of Health and Government. In June 1986 Cabinet agreed:

- 1 that all future legislation referred to Cabinet at the policy approval stage should draw attention to any implications for recognition of the principles of the Treaty of Waitangi;
- 2 that departments should consult with appropriate Maori people on all significant matters affecting the application of the Treaty;
- 3 the financial and resource implications of recognising the Treaty could be considerable and should be assessed wherever possible in future reports.^[1]

The Board of Health similarly recommended that the articles of the Treaty of Waitangi be recognised as a basis for good health, and in its April Report the Royal Commission on Social Policy^[2] saw the Treaty as relevant to all social policies including health.

Te Urupare Rangapu/Partnership Response outlined Government's commitment to honour the Treaty of Waitangi.

Article 1 provides for the Government to govern. As Crown agents, area health boards and regional health authorities are to be regarded as arms of Government with the rights and responsibilities prescribed in Article 1. The structure and composition of the Board, its committees and services, and the ways in which Maori people participate in its decision-making activities need exploration.

Article 2 provides for continuing Maori authority, not only for physical properties such as lands and forests but also for cultural and social matters. Tribes will undoubtedly wish to expand their health programmes and issues of funding, co-ordination and co-operation will arise.

Article 3 is about equity and the health of Maori men, women and children. It extends beyond a narrow focus on legal entitlement alone, and moves on to concern for health outcomes and the reduction of current health disparities. Active protection is an important aspect of Article 3 – an expectation that positive, proactive steps will be taken to ensure the maintenance of good health.

Using these three articles as a basis for further consideration, it is possible to focus on three aspects of Maori health policy:

- Maori participation in health policy and planning (an Article 1 issue);
- Maori development and policies for health (Article 2);
- Active protection (Article 3).

For Maori people, the Treaty articulates their status as tangata whenua (indigenous people), guarantees their rights with respect to land, water, forests, fisheries and other treasures, and confirms their rights to mana motuhake (self-determination). The signing of the Treaty by both Maori and Pakeha was seen as the recognition of a partnership of equals and the basis for the relationship between the two races.^[3] Implicit within the Treaty were the concepts of equity, partnership, and economic and cultural security, all of which contributed importantly to hauora (spirit of life/health). Poor standards of Maori health may therefore be regarded in part as non-fulfilment of these Treaty concepts and obligations.

In recent years, a Maori concept of health has been emphasised and health authorities are being urged to re-think basic attitudes to health and health care along cultural and ethnic lines. Tribal authorities have been advocated as custodians of Maori health^[4] and more emphasis on culture as a component of health has been recommended for the curricula of training health professionals.^[5] The Department of Health has made a commitment to the development of a bicultural health system and workforce and has emphasised the implications and importance of the Treaty of Waitangi as the basis of a partnership in health between Maori people and others in New Zealand.^[6-7] There have been strong calls too for more effective involvement of Maori people in health planning, a critical factor if the health needs of many Maori people are to be adequately met. Basic to this aim is the recognition that health cannot be imposed on a community but must develop in an acceptable manner from within in response to problems perceived at a local level.

Maori concept of health

In traditional Maori terms, health is an all-embracing concept which emphasises the importance of the wairua (spiritual), whanau (family),

hinengaro (mental) and tinana (physical) aspects.^[8] Modern terminology refers to this concept as 'holistic' which contrasts with the traditional western model in which only the physical aspects of health and sickness are emphasised. From the Maori viewpoint, issues involving te whenua (land), te reo (language), te ao turoa (environment) and whanaungatanga (extended family), are central to the Maori culture, central to health and deeply rooted in the principles of the Treaty of Waitangi. These views of health were clearly delineated in March 1984, at the Department of Health Seminar on Maori Health, Te Hui Whakaoranga, in Auckland.^[9]

While some may believe that the Maori concept of health has little relevance in today's world, it should be noted that the concept emphasises health promotion and disease prevention, measures of fundamental importance considering the impact that adverse lifestyles have been shown to have on Maori health.^[9] Successful health promotion also depends on people actively identifying their own health needs and priorities. As a result, innovative systems for health care and health education have arisen which not only promote healthy lifestyles but do so in a culturally sensitive and appropriate environment.

Terminology and power

In the past, the health service in this country has been able to define what health is and therefore what disease is. This has meant that the accompanying terminology has always been related to the culture of the health system. 'They who name the names have the power to control the meanings.'

As the Maori population has increased, particularly since the antituberculous drugs and BCG became available in the 1950s, the Maori requirement for change in service delivery has strengthened. Adjustment within the health service has produced a series of ideas about the method of change, and descriptions of change have varied. The popular use of Eric Schwimmer's term 'bicultural' has been interpreted by many New Zealanders to mean that some knowledge of the habits and customs of Maori people and even acquisition of Maori language would enable acceptable service delivery. This has not proved successful and indeed has increased the sense of powerlessness in some Maori when confronted by Pakeha health professionals

who are 'informed' on traditional Maori matters. Phrases such as cultural awareness, cultural sensitivity and culturally appropriate are consistently used by people in the health service to define the type of service they wish to give to Maori. It is assumed by the health service that Maori health needs will be met if health professionals maintain control of service and Maori advise the health service on the ways in which Maori want that service to be delivered. Health professionals have accepted that some change described as culturally appropriate, or sensitive, needs to be made but that essentially the system will remain unaltered.

Maori people have defined a term which is in line with the accepted views of legal safety, ethical safety and physical safety. The concept of 'cultural safety' has been offered as a further category of service delivery. Inherent in this is the idea that the culturally at-risk group defines the difficulty they have with service delivery.

A further difficulty for many Maori is the use of war language in the delivery of health services. If a group is continuously being defined as a 'target group' and subjected to 'campaigns' and 'blitzes' as the result of 'strategies' it is difficult to believe as one Maori said, that the wars are over. This type of terminology does not convey ideas of consultation and collaboration with the health service, nor of *tino rangatiratanga*. It is inherently pejorative and reinforces the sense of powerlessness Maori often feel in relation to the health service.

The resiting of health clinics on *marae* has been seen by many Pakeha health workers as a way to take service to the people. However, many Maori believe this has been unsuccessful because frequently nothing has changed except the location. This was brought to the attention of the review team. In contrast with the *marae*-based services which have been 'imposed' by Pakeha health professionals in some areas, a *marae*-based health service could be run by Maori with Health Development Unit support, such as the service initiated in the Porirua area.

What are Maori cultural values?

It is extremely difficult to assess the 'cultural values' of any individual Maori. It is impossible to assume that a Maori person, like any other, will react in a predictable way in any given situation. Further-

more, each iwi differs to some extent in values and belief systems.

There is a range of people with seemingly different views and values who identify themselves as Maori, from those who are rural and marae-based, to urban families with or without marae links, and to 'gangs' or 'street kids' or 'activists'. The health system must be adequately prepared to give culturally safe service to an often disparate group which has a common claim to and identification with Maoriness.

An understanding of this broad interpretation is necessary to give culturally safe service. The education of health workers must include an accurate understanding of the history of the colonial process and the settler government of this country and the subsequent impact upon the tangata whenua. It is important to avoid the creation of the idea that there are such things as a typical Maori health status and a standard approach to Maori health care, although guidelines can be useful.

Health workers also need careful education in understanding the Maori vision of tino rangatiratanga or Maori control of Maori destiny. Many Maori are becoming very clear about the type of health service they want and are prepared to work steadily to change existing services to suit Maori needs. Many Maori feel that it is not possible to obtain culturally safe services while those services are completely controlled by Pakeha who are unaware of these issues. The paradox in health for Maori is to be constantly told to take responsibility for their own health but not to have access to the resources to do so.

Traditional Maori cultural values have been well documented by anthropologists and academics. However, many Maori today are living in urban situations, some two to three generations removed from the traditional culture. It is estimated that at least 80% of Maori are now urbanised, a large percentage of these people having developed their own vision of Maoriness and cultural practice in response to life in town. Health services for Maori in towns need to be based on their specific needs and expectations as urban Maori rather than on 'traditional' values.

Many of these people and their circumstances have been placed in the 'too hard basket' by the health service. It is probable that a large proportion of Maori asthmatics come from this group.

Maori health initiatives

For many Maori people there are both cultural and economic factors which inhibit their use of existing health care services. As a result, there has been a strong commitment within the Maori community to become more involved in both the planning and delivery of health care. In 1981, a strong case was made for the development of community-based health programmes sensitive to the needs of Maori people at a local level.^[10] Many interesting programmes have now developed^[11] but chronic lack of funding has been a real barrier to progress.

Marae-based health centres at Waahi and Rotorua are closely associated with tribal organisation and development. The Waahi project has been supported by both the Departments of Health and Labour, and a priority has been the training of women from the local community to become Nga Ringa Aroha (those with loving hands). The training programme integrates Maori cultural values and beliefs, traditional Maori healing practices and modern preventive health knowledge. The latter has been provided, in part, by interested staff at Waikato Hospital. Nga Ringa Aroha not only promote a Maori view of health within their community, but also teach preventive health measures and strengthen links and understanding between health professionals, health services and the local community.

The Rotorua health centre was established by the Maori Women's Health League after discussions with different iwi (tribal), hapu (subtribal), whanau (family) and interested people living in the area. The centre's aims are similar to those at Waahi, with emphasis on a Maori perspective of health and health promotion and disease prevention activities.

Ngati Raukawa people have been interested for some time in documenting indices of health among their own people and have completed hapu and iwi surveys. The main aim of these surveys has been to gather information about the general status of each hapu and iwi and of the runanga as a whole. Information about aspects of personal health, access to health care and use of traditional remedies has helped build up a health profile for the runanga as a prerequisite to future planning.^[8]

The Raukawa Trustees established a centre of higher learning, Te Wananga o Raukawa, in Otaki in 1981; a re-establishment of an ancient institution, Te Whare Wananga, the original and most senior of which was Rangiatea. Te Wananga o Raukawa offers many courses including one in health studies which emphasises both traditional Maori and modern western concepts of health. The health curriculum includes sections on te reo (language); nga putake (foundations of health); whanaungatanga (family health); strategies for prevention; planning for health; and health promotion.^[12]

The Maori Women's Welfare League completed an important survey of the health of Maori women and their families,^[13] with major support from the Medical Research Council of New Zealand. This study provided a model for future research initiatives and was a positive example of Maori involvement in all stages of the planning and implementation of research projects.

A recent and innovative initiative in the Maori health area is the Waiora programme, which integrates all dimensions of health and aims to raise the self-esteem of Maori people, in particular Maori youth, by using two main strategies. The first involves community-based activities which encourage Maori people to re-establish and strengthen their cultural, tribal and family links. The second entails promoting a positive image of Maori people, using television as a medium. The Maori response to these television programmes has been very positive indeed.

At Manuariki there is a kura wananga (a special school of learning) which trains kai awhina (assistants) in traditional healing methods. Their particular skills are recognised as being important for people who require spiritual and cultural sustenance as part of the healing process. Many hospitals recognise the worth of these skilled people and view their services as being complementary to modern western medical practices.^[14]

There are many other community initiatives based as much on traditional Maori values as on contemporary modern health education. Importantly, they are initiatives which belong to the people and which emphasise the health priorities of relevance to that particular marae, tribe or organisation. They observe Maori protocol and depend heavily on tribal elders for support, guidance and sanction.

Classification of ethnicity

There are inconsistencies in the classification of ethnicity in New Zealand's statistical collection systems.^[15]

Ethnic statistics collected by the National Health Statistics Centre classify people of half or more Maori origin as being Maori and people of less than half Maori origin as non-Maori.

Some ethnic data depends on the accurate completion of forms by funeral directors and hospital admission staff. These people often make decisions based only on the appearance of their client. Maori are not easily identifiable by appearance and many would take umbrage at being identified as belonging to any other culture. Similarly there are Maori who choose during certain parts of their personal development, not to identify as Maori, although they are clearly of Maori descent. Being Maori is a psychological as well as a physical process and it is constantly changing.

The limited studies undertaken looking at this problem suggest that Maori numbers are under-estimated in health statistics.^[15] Accordingly, it is probable that the differences in health status between the Maori and non-Maori populations are actually wider than indicated in official statistics.

As the number of research studies in Maori health increases, the question of the classification of Maori ethnicity has become a bigger issue. It is suggested that some definition be adopted, such as 'a person who has Maori ancestry and who chooses to identify as Maori shall be considered to be Maori'. Much further study and discussion with Maori people should take place on this issue. Thereafter, discussion with ethical committees about requirements and standardisation should occur.



SECTION 2

Te mate huango

Asthma



Whaka-Maharatanga
Marae, Te One
September 1990

CHAPTER 2

Prevalence and causes of asthma

People must know about asthma.

Kirihaehae – 13 October 1990

Summary

Asthma is a disease of the airways in the lungs; the main symptom of which is a difficulty in breathing. The evidence that is available suggests that asthma is as prevalent in New Zealand as it is in other countries, and the prevalence is also similar in Maori and Pakeha children (although asthma may be more common in Maori adults). However, asthma is more severe in Maori people, hospital admission rates are higher, and until recently the death rate was higher. The most likely explanation for this is inadequate access to appropriate health care and a lack of asthma education available to Maori people.

What is asthma?

Asthma is a disease of the bronchial tubes (also known as the 'airways') in the lungs (see Figure 1). In people with asthma, the airways are twitchy or irritable. In an asthma attack these airways narrow (see Figure 2) and it becomes difficult to breathe. Thus, asthma usually involves difficult breathing which gets better or worse from time to time. Asthma is often characterised by 'wheezing' which is a high-pitched whistling sound heard during breathing (especially when breathing out). However, asthma does not always cause wheezing and it may lead to other symptoms such as shortness of breath, or coughing, particularly in children. Asthma usually develops in early childhood, but can develop at any stage in life. More than 75% of children who develop asthma symptoms before age seven no longer have symptoms by age 16.^[16]

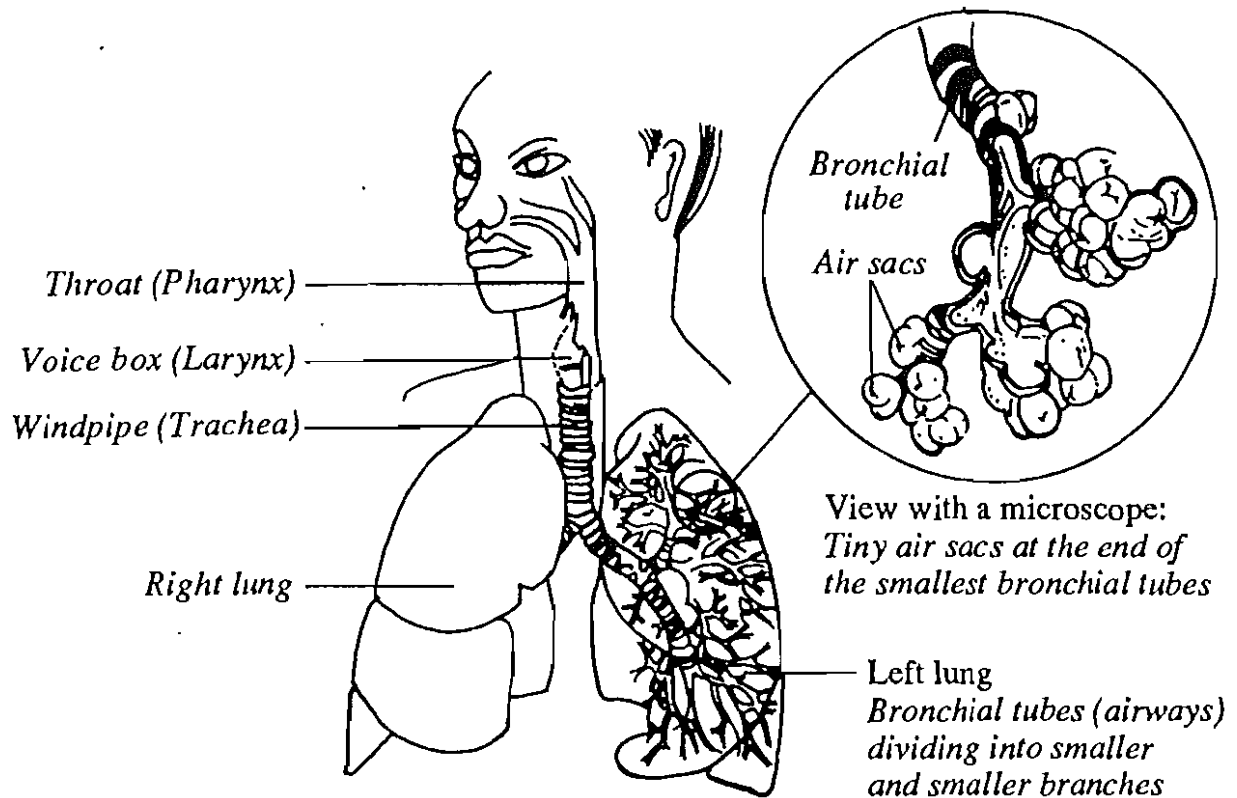


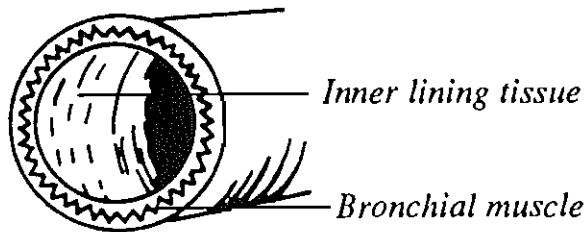
Figure 1: The lungs and bronchial tubes (airways)

Source: *What is asthma?* New Zealand Asthma Foundation

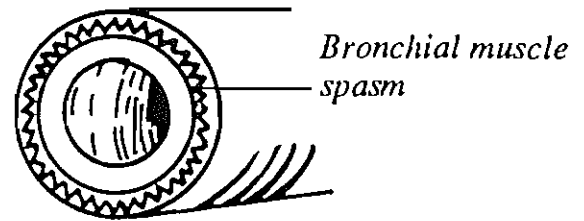
There are three reasons why the airways may narrow in people with asthma: the muscles around the airways tighten (bronchospasm); the tissue lining the airways becomes inflamed and swollen; and mucous (or phlegm) blocks the airways.

Until recently it was believed that bronchospasm was the main problem in asthma. Thus, asthma treatment was aimed at relaxing the bronchial muscles, usually by using a class of drugs known as beta agonists. These drugs are known as 'relievers' because they can relieve an acute attack. However, it is now thought that the inflammation of the tissue which is lining the airways and the mucous blocking the airways are the most important problems in asthma. As a result, much more emphasis is being placed on reducing these effects, usually by using two classes of drugs: corticosteroids and sodium

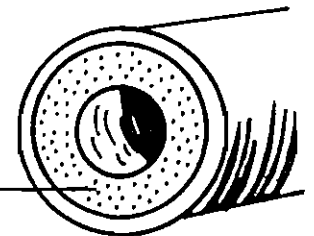
A normal bronchial tube



Causes of bronchial narrowing in asthma

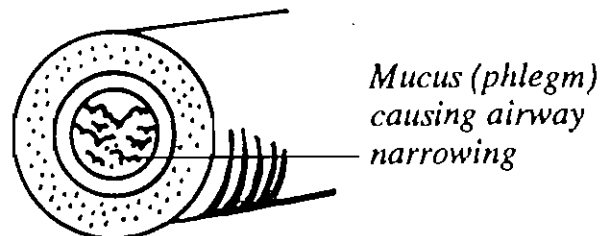


Swelling of
the inner
lining tissue



The windpipe and bronchial tubes have an inner lining layer which is similar to the inside of the mouth.

The walls of the bronchial tube contain a layer of muscle

**Figure 2:** Normal airways and narrowed airways

Source: *What is asthma?* New Zealand Asthma Foundation

chromoglycate. These drugs are known as 'preventers' because they can keep the asthma under control and prevent asthma attacks from occurring if they are taken regularly. Asthma drugs are discussed in more detail in the next chapter.

What causes asthma?

Asthma has been around for thousands of years, but little is known about why it occurs. Asthma appears to be partly hereditary since it is more common in people who have a parent or grandparent with asthma. There are also a number of factors (both allergic and non-allergic) which may cause a person to develop asthma, or trigger an

asthma attack in people who already have asthma and have become sensitised to particular factors.

Table 1: Some factors which can cause asthma attacks

<i>Allergic asthma triggers</i>	<i>Irritant asthma triggers</i>	
	<i>Chemicals</i>	<i>Other factors</i>
House dust mites	Dusts	Colds
Pollens	Fumes	Viral infections
Grasses	Tobacco smoke	Temperature
Animal dandruff	Air pollution	Exercise
Moulds	Sulphur dioxide	Certain foods
Flour	Ozone	Stress/excitement
Grain dusts	Chlorine	
Isocyanates	Ammonia	
Resins	Formaldehyde	
Enzymes	Solvents	
Smelter fumes	Paint fumes	
	Petrol	
	Formalin	
	Perfume	
	Scented soaps	
	Certain drugs (eg aspirin)	
	Some agricultural sprays (eg organophosphates)	

Note: Different factors can cause asthma in different people. These factors will only cause asthma attacks in people who have become sensitised.

The allergic factors include pollens, grasses, moulds, animal dandruff, animal urine, and house dust mites. The non-allergic factors include exercise, changes of temperature, air pollution, viral infections, dust, fumes, tobacco smoke and certain foods (see Table 1). Allergic factors can also cause other conditions, such as hay fever, and these conditions may therefore be associated with asthma. However, not all people with allergies develop asthma, and not all people with asthma are allergic.

Many of the factors which trigger asthma are themselves related to poverty and inadequate housing.^[17,18] In fact, the percentage of people who have asthma does not appear to be related to poverty, but severe asthma^[19,20] and asthma deaths^[21] are more common among manual workers. Asthma can also be caused by exposure to substances at work, including smelter fumes, isocyanates, wood dust, and flour.

The factors which trigger an asthma attack are different for different people. Submissions to the review committee mentioned many different factors which provoke asthma; including those listed in Table 1. In one study of asthma in New Zealand children,^[22] the most commonly mentioned triggers were the weather (70%), infections (61%), stress or excitement (25%) and dust (24%).

Most people with asthma have a condition known as bronchial hyper-responsiveness (BHR). This means the airways are irritable and overresponsive to various factors that can produce inflammation in the tissue that lines the airways. It appears that allergies and the other factors listed above, including some chemicals, can cause a person to develop BHR. Once BHR has developed, it may also be triggered by other factors, as well as the factor that initially caused it to develop. Although BHR occurs in most people with asthma, the two conditions are not exactly the same: some people with asthma do not have BHR, and some people with BHR do not have asthma. Despite these limitations, BHR is often used in prevalence studies, to work out how common asthma is in a community.

Is asthma becoming more common?

Few studies of asthma prevalence in different communities in New Zealand have been done, and of those studies not all used the same methods. In any particular community, different answers will be obtained depending on whether BHR testing is done, and which question is asked about asthma (eg 'Do you have asthma?', 'Have you ever been diagnosed by a doctor as having asthma?', 'Does your chest ever sound wheezy?'). This problem is even worse when attempting to compare different ethnic groups, since the words 'asthma' and 'wheeze' are difficult to translate and equivalent words do not exist in some languages. One new method for measuring asthma prevalence involves the use of a video questionnaire.^[23] This

appears to be a promising method which can be used to ask about asthma, while avoiding the usual translation problems.

Several major international studies are currently under way, using either standardised written questionnaires or video questionnaires, which will compare asthma prevalence in different countries, and in different ethnic groups within countries. Until these studies are completed, it is difficult to know whether asthma is becoming more common, and whether it occurs more often in particular countries or ethnic groups.

However, some researchers have attempted to draw tentative conclusions using information which is currently available.

One review of studies of children and adolescents in the United Kingdom concluded that, although there was some evidence that the percentage of children diagnosed as having asthma had increased, there was little evidence that the overall prevalence of wheezing illness in children had increased.^[24] However, several other studies in the United Kingdom^[25] and New Zealand^[26,27] have found evidence that asthma prevalence has increased in recent years. In particular, a survey of asthma prevalence in school children in Wairoa found that the prevalence of reported asthma or wheeze increased from 26% to 34% between 1975 and 1989.^[27]

Thus, it is possible that diagnosed asthma and wheeze has increased in New Zealand and other countries in recent years, but the evidence for this is uncertain, and the increase does not appear to be very large. Further studies are needed to find out whether asthma is increasing and, if so, why.^[28]

Is asthma becoming more severe?

Although it is not clear whether the number of cases of asthma in general is growing, there is evidence that severe asthma is on the increase. In particular, admission rates are increasing in many different countries.^[29]

Trends in admission rates are difficult to interpret, since these depend on medical practice as well as the severity of the asthma. Many asthma attacks which are severe enough to require a hospital admission do not actually result in an admission for asthma, either because asthma has never been diagnosed, the person with asthma

does not seek medical help, or because their general practitioner does not refer them to a hospital. The worldwide increase in asthma admission rates may be occurring merely because doctors have become more aware of the life-threatening nature of severe asthma attacks, and have begun to refer patients to hospitals more often. However, a review of data on hospital admissions for childhood asthma in the United Kingdom concluded that the increase in admissions could not be explained by changes in medical practice alone, and that it appeared that severe asthma attacks were occurring more frequently in asthmatic children.^[24] Similarly, a New Zealand study found that the recent increase in hospital admissions for asthma in children was not due to less severe asthmatics being admitted, but that the severity of acute attacks seemed to have actually increased.^[30]

The death rate from asthma has also increased in a number of different countries.^[31] This increase has occurred steadily since the advent of modern asthma treatments in the 1940s,^[32,33] but it has been particularly strong in the last 10 years. Most researchers have concluded that the increases are real and not due solely to changes in the diagnosis or classification of asthma.

The reasons for this apparent increase in severe asthma are unclear. It is possible that factors that trigger asthma attacks have become more common in recent decades, including viral infections, chemical exposures, and house dust mites. Furthermore, the advent of relieving drugs, and particularly the beta agonists, may have led to greater exposures to such asthma triggers. Before these drugs were introduced people with asthma tended to avoid the factors which caused their asthma, whereas nowadays people with asthma tend to obtain relief of their symptoms with asthma drugs, while continuing to be exposed to asthma triggers (such as house dust or pollen).

A more worrying possibility is that asthma drugs themselves may have had a more direct role in the increase in asthma severity and deaths.^[34] The relieving drugs, and particularly the beta agonists, are very effective in relieving asthma symptoms in an acute attack, and have clearly improved the quality of life for asthmatics. However, regular use of beta agonists and other bronchodilators may make asthma more severe,^[34,35] which could explain the gradual increase in asthma death rates in many countries particularly since beta agonist sales increased dramatically at the end of the 1970s.^[36] However, this

hypothesis is currently very contentious, and such adverse affects have not been demonstrated with all beta agonists at this time.

In addition to the gradual increase in asthma deaths which has occurred over the last few decades, six different countries (including New Zealand) experienced sudden epidemics of asthma deaths in the 1960s. The reason for these epidemics was never conclusively established, but it was noted that these epidemics coincided with the marketing of a high-dose preparation of a beta agonist known as isoprenaline forte.^[37] This drug had major side effects on the heart which can be dangerous in people with asthma who become hypoxaemic (short of oxygen) in a severe asthma attack.

A second epidemic of deaths occurred in New Zealand in the 1970s. This has been attributed to fenoterol, another beta agonist which has major side effects on the heart and was marketed in high doses. The drug was heavily used in New Zealand, but not in other countries.^[38-40] As a result of studies undertaken in New Zealand, the availability of fenoterol has now been severely restricted by the Department of Health, and the death rate now appears to have declined markedly.

Although it is not certain that modern treatment methods have caused an increase in asthma severity and asthma deaths, there is considerable evidence that they have contributed to these events.^[41] Therefore, emphasis is currently shifting from the use of beta agonist drugs which provide relief of symptoms but may increase chronic asthma severity, to the use of inhaled preventive drugs which can prevent or relieve the underlying inflammation and thus prevent asthma attacks from occurring (see Chapter 5).

Is asthma more common or more severe in Maori than in Pakeha?

Many people believe that asthma is much more common in New Zealand than in other countries, but there is little evidence to support this belief. One study found that childhood asthma was more common in New Zealand than in the United Kingdom,^[42] and another study found that childhood asthma was more common in Hastings than in Wales.^[43] However, the differences were not large (17% versus 12% for asthma, and 27% versus 22% for wheeze in the Hastings study),

and other studies have found that asthma prevalence in children was similar in New Zealand, Australia and Canada.^[44,45] A recent study (Pearce et al, unpublished data) found that childhood asthma prevalence was the same in Wellington, Sydney and London.

Similarly, it is often assumed that asthma is more common in Maori than in Pakeha New Zealanders, but the data which is currently available suggests that the prevalence of asthma is similar in Maori and Pakeha (see Table 2). Studies in Lower Hutt,^[26] Auckland,^[46,47] Rotorua,^[48] Wairoa^[48] and Hastings,^[43] and Wellington (Pearce et al, unpublished data) found a similar prevalence of BHR and past or present symptoms of asthma in Maori and European children. However, a further survey in Wairoa in 1989 found that reported wheeze has particularly increased in Maori children.^[27,49]

Table 2: Studies of asthma prevalence in children

<i>Study</i>	<i>Location</i>	<i>Measure of asthma prevalence</i>	<i>Maori Prevalence</i>		<i>Pakeha Prevalence</i>	
			<i>N</i>	<i>(%)</i>	<i>N</i>	<i>(%)</i>
Stanhope et al ^[48]	Wairoa	Asthma or wheeze: questionnaire	478	27	237	24
Mitchell ^[26]	Lower Hutt	Asthma: questionnaire	90	12	686	14
Harrison et al ^[47]	Auckland	BHR and past or present symptoms: BHR testing and questionnaire	503	11	1062	14
Pattemore et al ^[46]	Auckland	Wheeze in last year	509	22	1084	16
Shaw et al ^[49]	Wairoa	Asthma or wheeze	328	36	107	27
Barry et al ^[43]	Hastings	Wheeze in last year	290	19	583	17

When considered together, these studies do not suggest that there are major differences in asthma prevalence between Maori and Pakeha children in New Zealand, although it appears that small differences may exist. It should be noted that many Maori people challenged this view in submissions to the review committee, and argued that asthma was more common in Maori people.

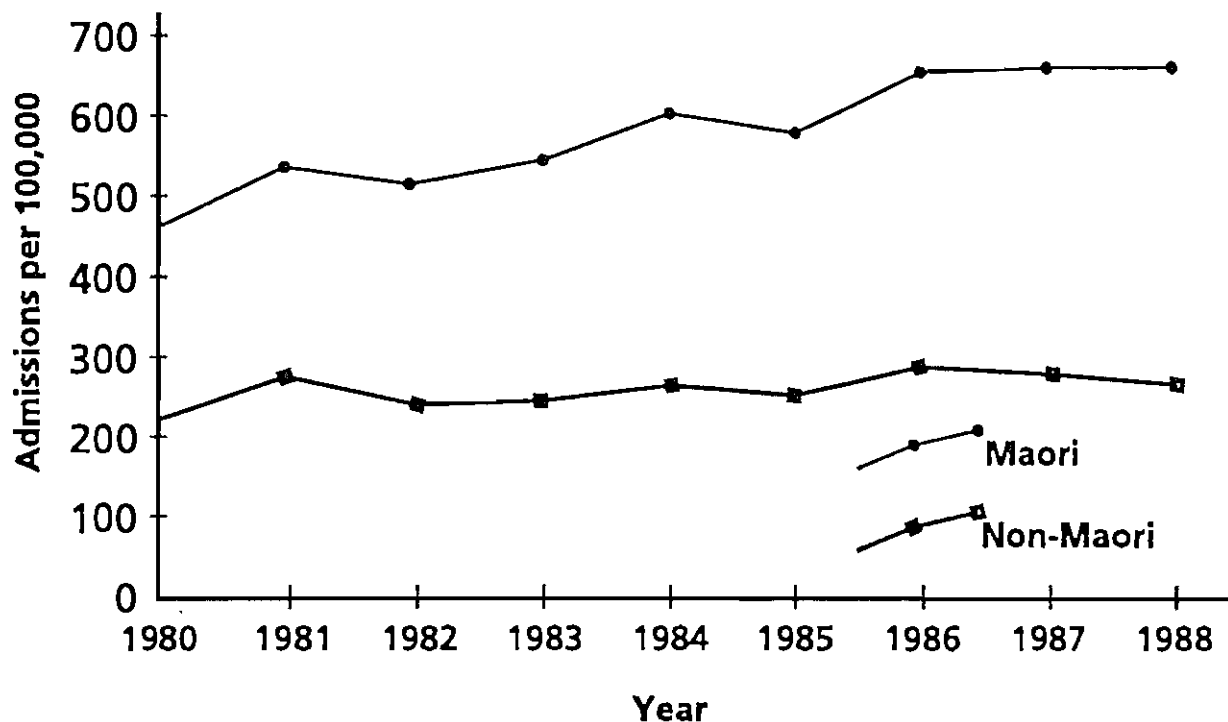


Figure 3: Asthma admissions 1980–1988, age 5–34

It should also be noted that the studies to date have all been on children. It is possible that asthma may be more persistent into adulthood or that late onset asthma could occur more often in Maori people. In this case, asthma prevalence is possibly more common in Maori adults than in Pakeha, even if it is not much more common in Maori children. In fact, there is some preliminary evidence for this (Neil Pearce, unpublished data).

These issues can only be clarified by further studies, some of which are currently in progress. However, at this stage, it should be noted that the available data is not necessarily at odds with reports that asthma is more common in Maori people. These reports mainly relate to obvious instances of wheezing and relatively severe asthma, and there is some evidence that asthma may be more severe in Maori people, even if asthma itself is not much more common. In particular, one study in Auckland found that the prevalence of asthma was similar in Maori and Europeans, but that the disease was more severe in Maori, as measured by severe BHR and the presence of asthma

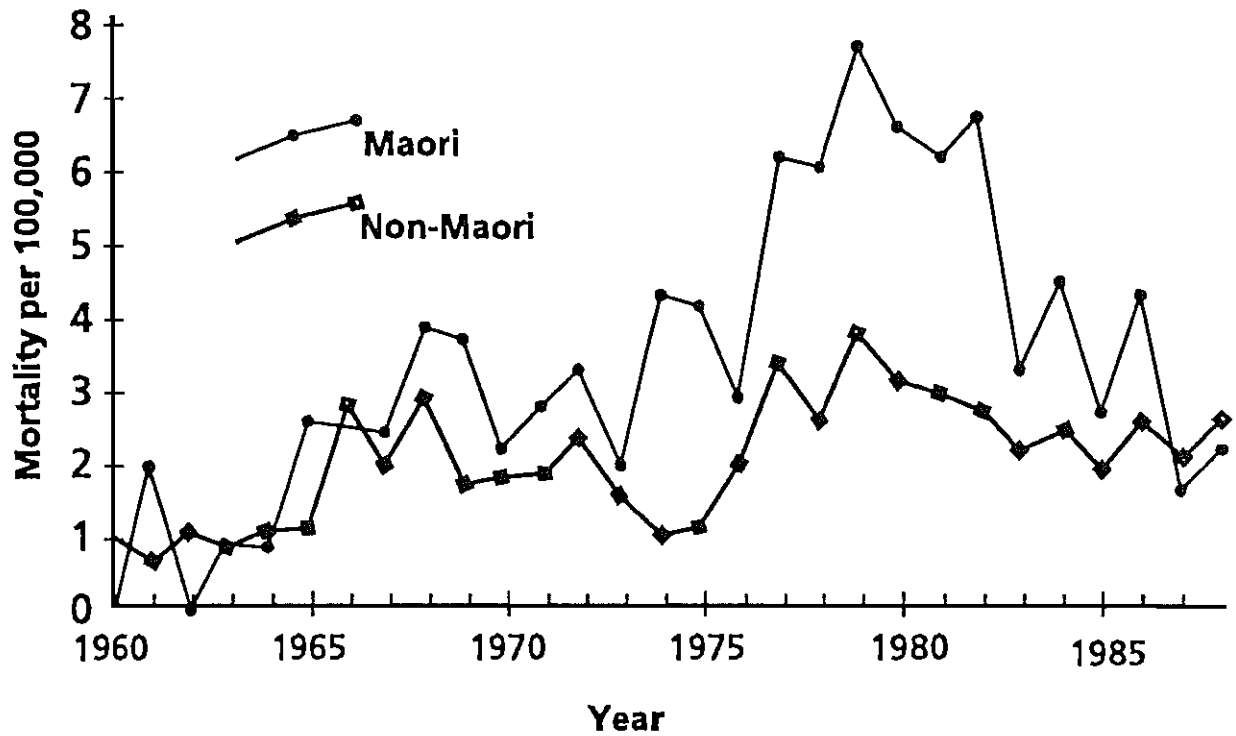


Figure 4: Asthma deaths 1960–1988, age 5–34

symptoms.^[47] However, these differences were not large enough to explain the ethnic differences in hospital admission and death rates.

Hospital admission rates for asthma, the length of stay, and re-admission rates are higher in Polynesian (Maori and Pacific Island) children.^[50] A national study found that the admission rate for asthma in Maori was about twice that of non-Maori.^[51] Recent trends in hospital admissions are shown in Figure 3 for Maori and non-Maori New Zealanders aged 5–34 years (most admission and mortality data concentrates on this age group since asthma is a major cause of illness and deaths in this age group and the classification of asthma death is very accurate). The figure shows that admission rates have been consistently higher in Maori throughout the period 1980–1988.

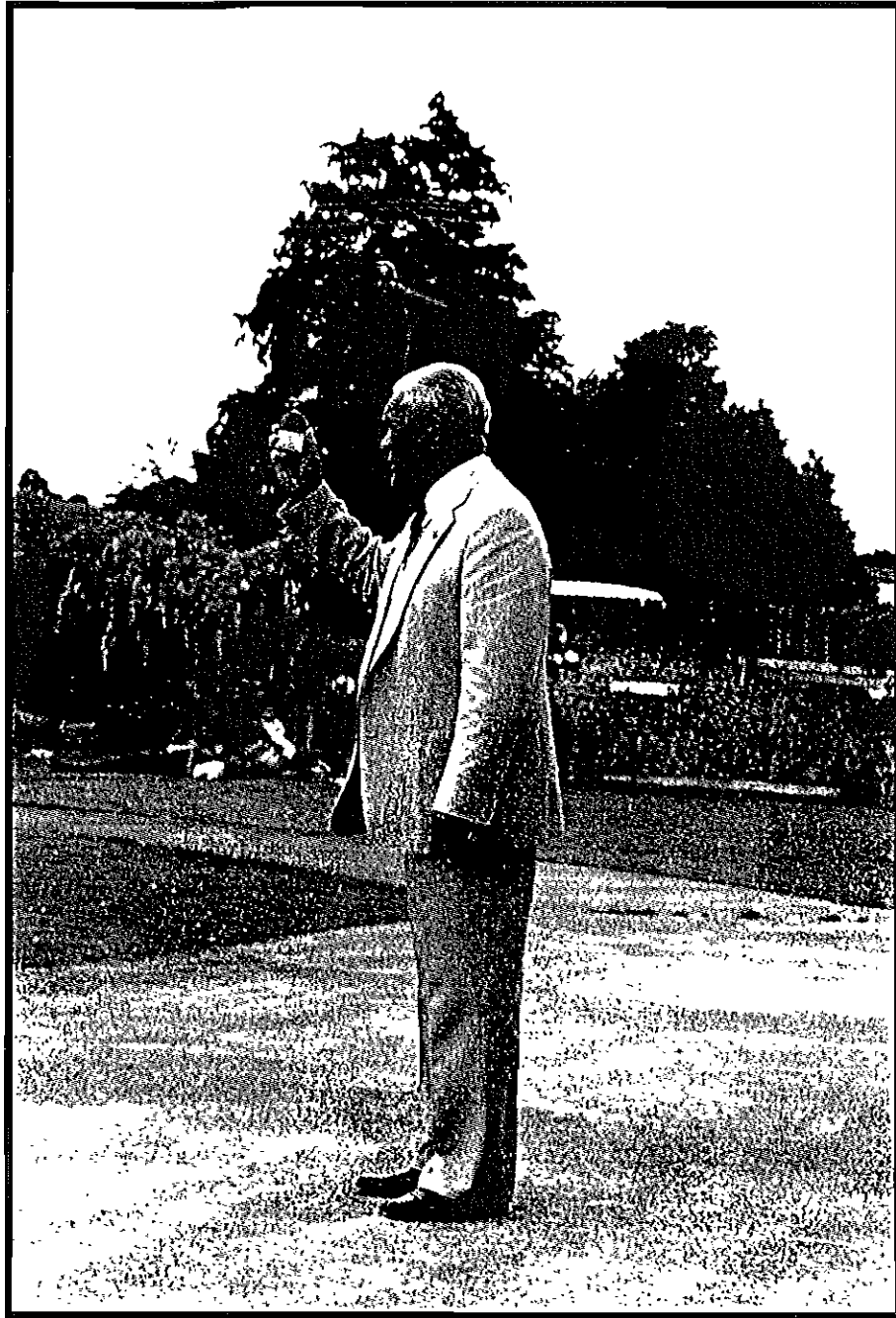
A number of researchers have reported that asthma death rates were much higher in Maori than in non-Maori, particularly in the early years of the epidemic of deaths which started when fenoterol was introduced in 1976.^[51–55] Figure 4 shows time trends in asthma deaths in Maori and non-Maori New Zealanders aged 5–34 years.

Maori death rates were high in the early years of the most recent (the second) mortality epidemic which started in 1976. Death rates for both Maori and non-Maori began to fall after the epidemic was identified as such in 1981 and patients and doctors were alerted to the possible problems of over-use of beta agonist aerosols. The death rate fell more rapidly in Maori people, perhaps because admission rates increased (see Figure 3), and the most recent data for 1988 shows that the death rate is now similar in Maori and non-Maori (see Figure 4). These death rates were still the highest in the world at that time, but the death rate appears to have fallen since the problems with fenoterol were reported in 1989 and the use of the drug restricted.

Discussion

In summary, available information suggests that asthma prevalence is similar in Maori and Pakeha children, or that any differences are likely to be small. However, little is known about asthma prevalence in adults, and it is possible that asthma symptoms may be more common among Maori people in this age group. Asthma appears to be more severe in Maori people, hospital admission rates are higher, and the death rate was higher until 1987. The explanations for the ethnic differences in asthma severity, have generally been sought in terms of the management of chronic asthma. In particular, it has been suggested that asthma may be more severe or life-threatening in Maori people due to inadequate access to appropriate health care and asthma education.





Rua Cooper demonstrating the importance of an inhaler, Kirihaehae Marae – October 1990

CHAPTER 3

Management of asthma

*We didn't know that there were
asthma specialists.*

Tunohopu – 28 September 1990

Summary

Asthma is increasingly being recognised as a disease involving inflammation of the airways. This inflammation can be reduced by using preventer drugs. Reliever drugs reduce the symptoms of asthma, but they do nothing to reduce the inflammation, and they may make the condition worse if they are used too often. A well-informed patient with a peak flow meter, a written management plan, and the appropriate medicines, is the best person to effectively manage asthma. The role of the health care worker is to inform the patient and provide the tools.

In this chapter various aspects of asthma management are discussed in light of recent changes in the understanding and management of asthma.^[56,59] In particular, it is increasingly being recognised that the person who has asthma is the best person to manage their asthma, in partnership with health professionals. A second major change has stemmed from the growing realisation that over-use of relieving medicines may make asthma worse, and may be particularly dangerous when these drugs are over-used in a bad attack.

Diagnosis of asthma

The key characteristic of asthma is usually difficult, noisy breathing (wheezing) which gets better or worse from time to time, and may also involve chest tightness and coughing. The most common way for

a doctor to diagnose asthma is by looking at the patient's medical history. Asthma can be diagnosed if there have been episodes of breathlessness, chest tightness, wheezing and cough, especially if these symptoms get worse after exposure to factors that can provoke an asthma attack. People with asthma often have fairly normal breathing between attacks, but may have severe breathing problems when an attack occurs.

Another way of diagnosing asthma is to monitor breathing over several weeks, using a peak flow meter. In this way, it is possible to work out how well the airways are working when symptoms occur. Large changes in the peak flow readings are a sign of asthma, particularly if there is a difference in the readings of at least 20%, either between the morning and evening peak flow readings, or after contact with something, eg a cat, house dust, pollen, or a cold, which is believed to be causing the asthma. Another sign of asthma is if the peak flow reading improves after use of a relieving asthma drug.

A peak flow meter can be particularly helpful to work out whether particular symptoms are due to asthma, for example, if a person wakes regularly at night coughing, or gets breathless and coughs with wheezing after exercise. If the peak flow falls markedly (more than 20%) at night (when the person wakes up), or by a similar amount after exercise, then this is strong evidence that the person has asthma. On the other hand, if there is little change in the peak flow when these symptoms occur, then it is unlikely that the symptoms are due to asthma.

Peak flow measurements

A peak flow meter measures how fast you can blow out. When your asthma gets worse, your airways narrow, you can't blow out so fast and your peak flow falls. This often happens before symptoms occur, so the peak flow meter helps asthma attacks to be detected early. Peak flow meters are available on prescription.

Figure 5 shows someone using a peak flow meter. Before you use it, you need to make sure that the marker has been set to zero; you then take as big a breath as possible, put your lips around the mouth-piece and blow as hard and fast as you can, trying to get all the air out of your lungs. You then read the peak flow from the position of the

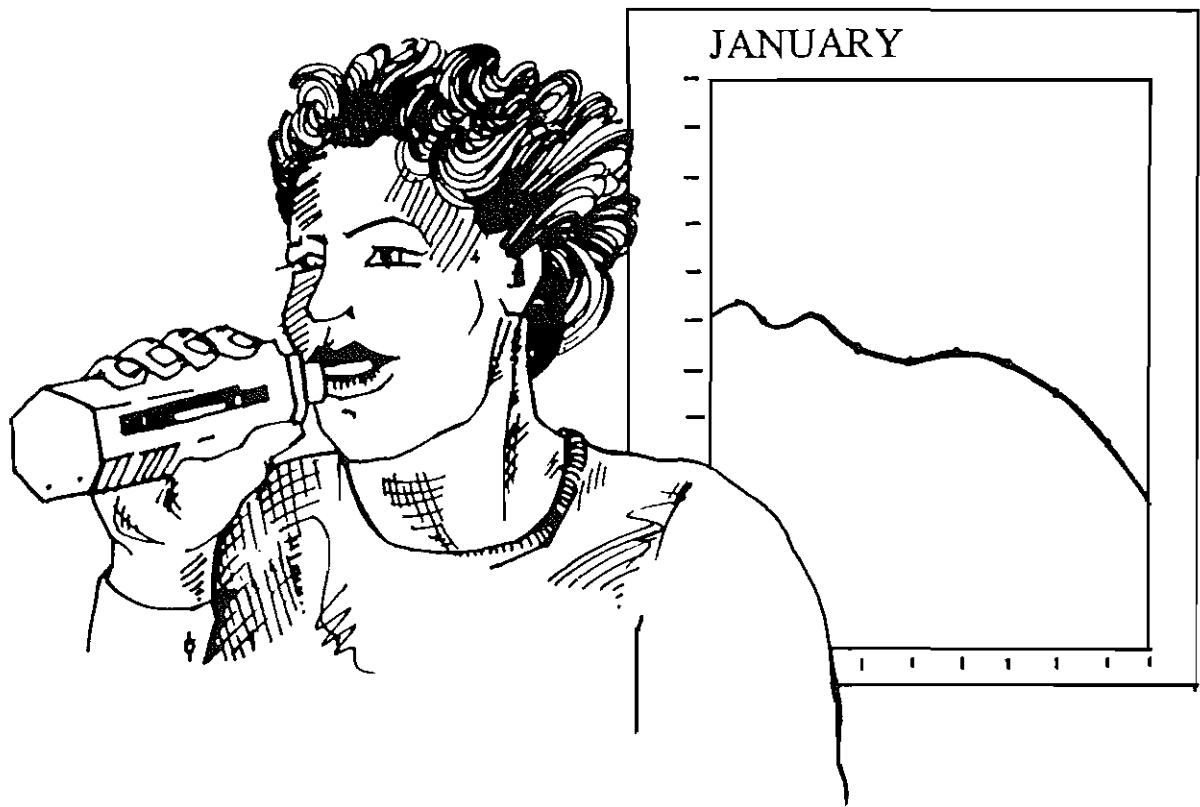


Figure 5: Using a peak flow meter

Source: *Questions and answers about asthma medicines*, New Zealand Asthma Foundation

marker on the scale. You usually do this three times and take the highest measurement out of the three. The 'normal' value for a peak flow varies a great deal according to age, sex and height. For example, the normal (predicted) peak flow in a 35-year-old man is about 600 (litres per minute) whereas the normal value in a 20-year-old woman is about 450. It is important to find out what your best peak flow value is. When your peak flow falls below this value, then you know that your asthma is getting worse.

Figure 6 shows some uses of peak flow readings. Chart A shows how peak flow measurements can be used to diagnose asthma. A single reading is not of much value, but a series of readings taken over several days or weeks may show large variations in peak flows. This pattern is typical of asthma.

Peak flow readings can also be helpful in identifying the factors which trigger or cause asthma. For example, if asthma is caused by fumes or dust at work, then the peak flow may go down during the

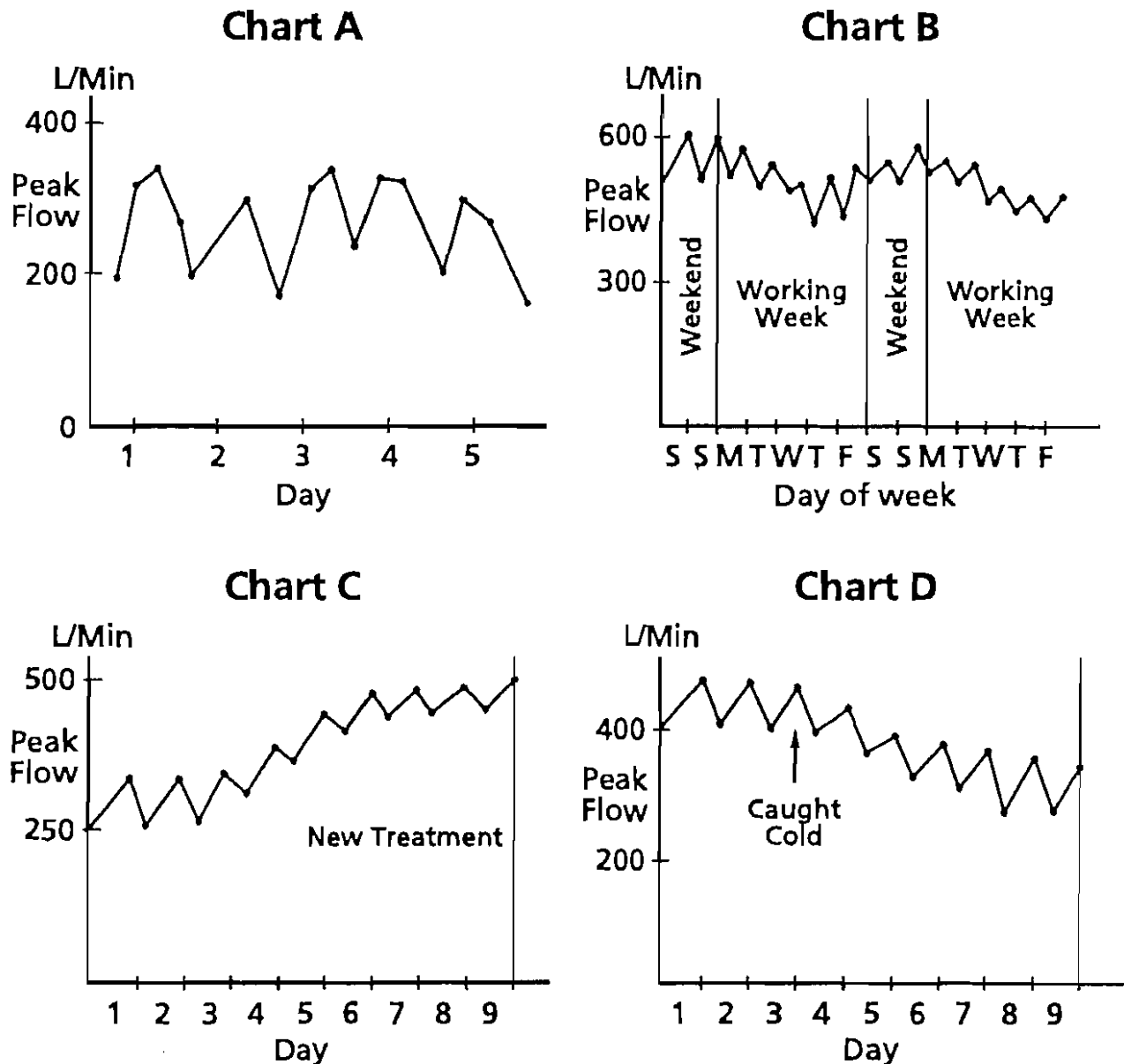


Figure 6: Some uses of regular peak flow readings

Source: *Peak flow measurement*, United Kingdom National Asthma Campaign

working week and recover in the weekend (Chart B). Similarly, the peak flow will increase when a person starts new preventive treatment (Chart C). Finally, regular readings can help detect an attack early before major symptoms develop (Chart D). This makes it possible to start or increase treatment early and thus avoid a bad attack.

Figure 7 shows an example of a slow onset asthma attack. The woman in question got a head cold on day five and started coughing at night. Her peak flow began to drop immediately (at point A), indi-

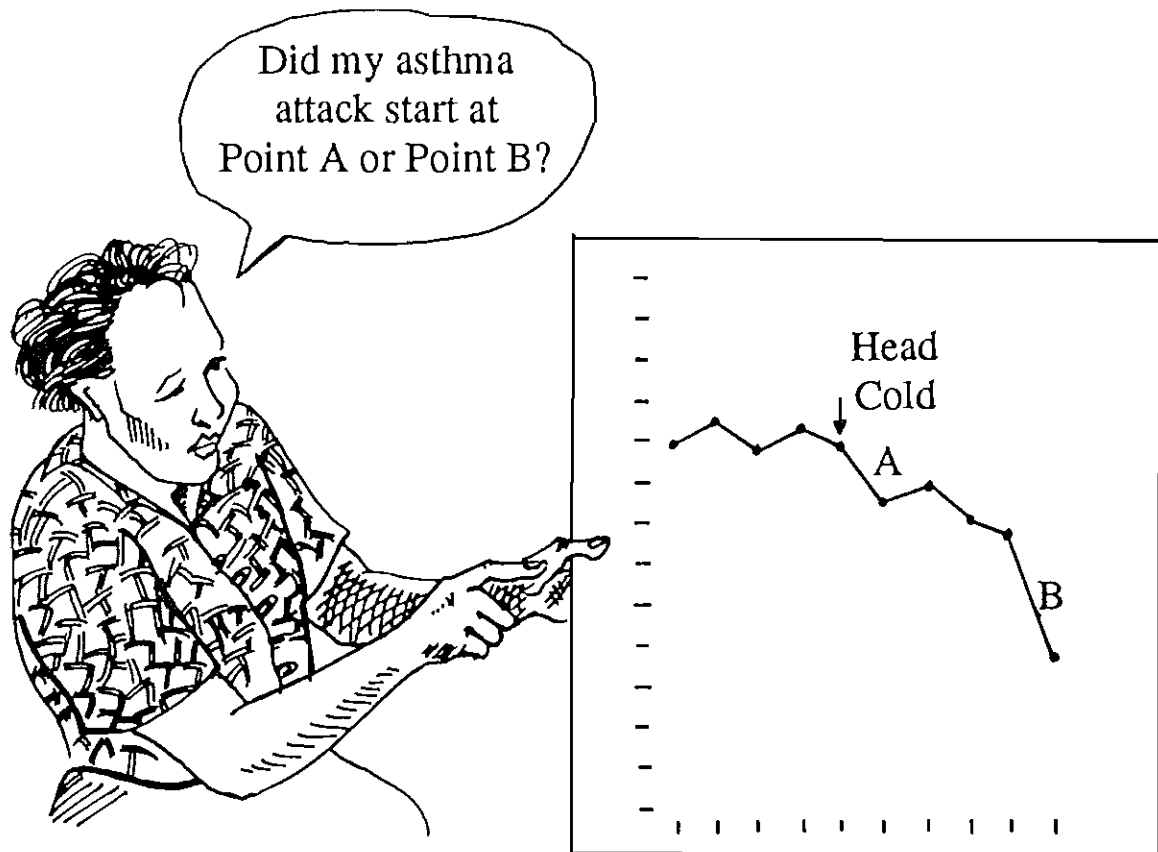


Figure 7: Keeping daily peak flow records to recognise attacks early

Source: *Peak flow measurements in asthma*, New Zealand Asthma Foundation

cating that her asthma was getting worse. However, she only began to feel wheezy on day 10 (at point B). She rapidly became distressed and when she saw the doctor in the afternoon she needed a nebuliser, an injection, and a course of prednisone tablets. Early treatment of the attack at point A might have stopped the attack before it got so bad.

Monitoring the severity of asthma

Asthma is very changeable, and people with severe asthma can go through periods when their asthma is quite mild and not very troublesome. Thus, once asthma has been diagnosed, it is useful to learn how to monitor its severity. This normally involves finding out how bad the symptoms have been, recognising what the different symptoms indicate, and taking peak flow measurements over a few weeks to see how great the variation in peak flow has been.

Table 3 shows some guidelines by which asthma can be classified

as severe, moderate or mild. For example, if a 50-year-old man has a best peak flow of 500, but on most days has some asthma symptoms in which the peak flow drops as low as 375, this would represent a

Table 3: Guidelines for classifying asthma severity

<i>Grade</i>	<i>History</i>	<i>Use of reliever medicines</i>	<i>Change in peak flow</i>	<i>Best peak flow (% of predicted)</i>
Severe	Wakes at night with wheeze, cough; chest tightness on waking in morning; hospital admission in last year; previous severe attack	more than four times a day	more than 30%	less than 70%
Moderate	Symptoms on most days	Needed on most days	20–30%	70–100%
Mild	Occasional symptoms; for example, only with exercise or colds	Needed occasionally	10–20%	100%

Source: Adapted from TSANZ [58]

25% drop from the best value of 500. Therefore, using the guidelines in Table 3, this man would be classified as having moderate asthma at the time of the monitoring.

Similarly, if a 30-year-old woman has a best peak flow of 350, this is about 70% of the normal (predicted) value for a woman of this age. If the peak flow sometimes drops as low as 250 (only 50% of the predicted value), or if she begins waking most nights with a wheeze or a cough, then she would be classified as having severe asthma at the time of the monitoring (using the guidelines in Table 3). It is this recognition of certain symptoms and changes in peak flow which indicates the severity of the asthma to the patient, family and doctor.

Achieving best lung function

Once asthma has been diagnosed, and its severity has been monitored, the next task is to restore the peak flow to its best possible

value. For example, the predicted value for the 30-year-old woman mentioned above is about 500. If she has a peak flow of 350, this is only 70% of the predicted value. However, it may be possible to raise the peak flow close to the predicted value by taking two puffs of a reliever drug. If the peak flow is still well below the predicted value after a reliever drug has been taken, then preventive therapy is required to restore normal lung function. This usually involves using inhaled preventer drugs which may be taken long term. For particularly severe asthma, a short course (one to three weeks) of oral steroids may be necessary to bring the asthma under control.

Management of chronic asthma

Once a reasonable peak flow level has been obtained and the asthma is under control, the main problem is to maintain it. Controlling the asthma involves three things: avoiding triggers and aggravating factors; regular measurements of peak flows; and drug therapy.

Avoiding triggers

Asthma attacks can be triggered, or made worse, by different factors, including tobacco smoke, pollens, grasses, animals, house dust mites, exercise, changes of temperature, viral infections, dusts, fumes, tobacco smoke, and certain foods. The triggering factors are different for different people. It is important to find out what the triggers are, and to try to avoid them. Triggers can often be identified by recognising symptoms such as breathlessness, chest tightness, wheezing and coughing, and by measuring peak flows after exposure to triggers. For example, you may identify your cat as a trigger if you develop breathlessness, chest tightness, wheezing or coughing after you have been in contact with your cat, and measure your peak flow at this time. If your peak flow has dropped substantially, eg by 20% or more, then the cat has triggered your asthma.

It can be helpful to make a list of things that trigger your asthma. Many triggers can be avoided once identified. In particular, if you have asthma it is important that you do not smoke, and that no one else in your house smokes.

Some asthma triggers, such as cold air, exercise, or emotional stress, are difficult to avoid; and exercise (particularly swimming) is a

good thing to do for most people with asthma. However, if asthma is triggered by exercise, this can be prevented by taking reliever drugs or sodium cromoglycate beforehand.

Peak flows

Once the asthma is under control it is helpful to keep measuring peak flow regularly. It is particularly important to do this at least twice a day when exposed to asthma triggers or when the asthma seems to be getting worse. In severe asthma, even more frequent measurements will be necessary.

Drug therapy

Very mild asthma can be treated by using a reliever drug to relieve the occasional symptoms. However, if a reliever drug is needed at least once a day, then this is a sign that a preventer drug is needed. Once the asthma is under control, preventer drugs can be reduced to the minimum level that keeps the asthma under control.

Low doses of inhaled preventer drugs have few side effects, and it is important to take these regularly to keep the asthma under control. A major problem with these inhaled preventer drugs is that many people don't have them, forget to take them, or simply don't bother, because they do not provide the immediate relief of symptoms which is obtained with the reliever drugs. In particular, many people stop taking their inhaled preventer drugs when they begin to feel well, and as a result the asthma may worsen and another severe attack may occur. One useful system is to place the preventer inhaler by the toothbrush so that using one will be a reminder to use the other. Another approach is to place the preventer inhaler at the bedside and to use it when getting up in the morning, and when going to bed at night. It is also a good idea to have extra preventer inhalers in your bag, in your car, or at work.

Asthma drugs

As previously discussed, the airways are twitchy or irritable in people with asthma. In an asthma attack, these airways narrow and it becomes difficult to breathe. There are three things that narrow the airways:

- the muscles around the airways tighten (bronchospasm);
- the lining of the airways becomes inflamed and swollen;
- mucous (or phlegm) blocks the airways.

Most asthma drugs are designed to treat one of these three asthma symptoms.

Sources of information

There are about 8000 different medicines which can be prescribed by doctors in New Zealand, and most doctors are familiar with only a few of them. Although the Department of Health publications (such as the *Therapeutic Notes* and the *Clinical Services Letters*) are excellent, they are only produced a few times a year, and the Department of Health generally has limited resources for giving independent information on asthma drugs to general practitioners.^[60] As a result, most general practitioners rely on drug company advertising to learn about new asthma drugs. For example, the *Therapeutic Notes* was only published twice in 1989 (a total of 30 pages), whereas a general practitioner typically receives 3kg of promotional material from drug companies every month.^[61] Drug companies in New Zealand spend about \$25,000 on advertising per general practitioner per year, a total of about \$45 million per year.^[61]

All this means that general practitioners do not always have the best independent information available when making prescribing decisions, and that prescribing can sometimes be influenced by advertising or other promotional activities. These issues have been drawn to public attention by a number of developments in recent years, one of which was the concern about the handling of safety issues associated with the asthma drug fenoterol which was found to be causing asthma deaths.^[60] More general concern has arisen recently about the category of asthma drugs known as 'relievers', which have been heavily promoted in New Zealand in the last decade, with a large increase in sales.^[36] Many patients were advised by respiratory physicians and pharmaceutical companies to use these drugs more often (four times a day), even though there was little evidence that regular use of these drugs is beneficial, and there is now some evidence that it may be harmful (see below). Recently there have been positive developments in the provision of independent information on

pharmaceuticals in New Zealand,^[62] but more resources are needed for the Department of Health and other organisations to provide an independent voice.

Reliever drugs

Until recently it was believed that bronchospasm was the main problem in asthma. Thus, asthma treatment was aimed at relaxing the bronchial muscles, using drugs known as bronchodilators (see

Table 4: Some reliever (bronchodilator) asthma medicines used in New Zealand

<i>Class</i>	<i>Brand names</i>	<i>Speed of action</i>	<i>Side effects</i>
Beta agonists	Bricanyl Ipradol Pulmadil Ventolin Respolin	Several minutes	These drugs are generally safe but there may be nausea, shakiness and rapid heartbeat. These side effects are particularly severe for some other drugs in this class (particularly Berotec and Duovent) and these drugs may be dangerous if over-used in an acute attack. This class of drug should ideally not be used regularly but should mainly be used for relief of symptoms.
Ipratropium bromide	Atrovent	10–15 minutes	No known side effects, but the effectiveness in relieving symptoms is also not particularly good.
Theophyllines	Choledyl Nuelin Somophyllin Theodur Theo-24	Several hours	Can cause nausea, shakiness, rapid heartbeat, particularly when taken together with beta agonists.

Source: Adapted from *Asthma medicines in a nutshell*, Asthma Foundation of New Zealand

Table 4). These drugs are known as ‘relievers’ because they can relieve an acute attack. Relievers are usually sold in blue packaging in

New Zealand, but this is not always the case and some relievers are sold in packaging of a different colour.

The most common type of bronchodilators are the beta agonists such as Ventolin (salbutamol), Respolin (salbutamol), or Bricanyl

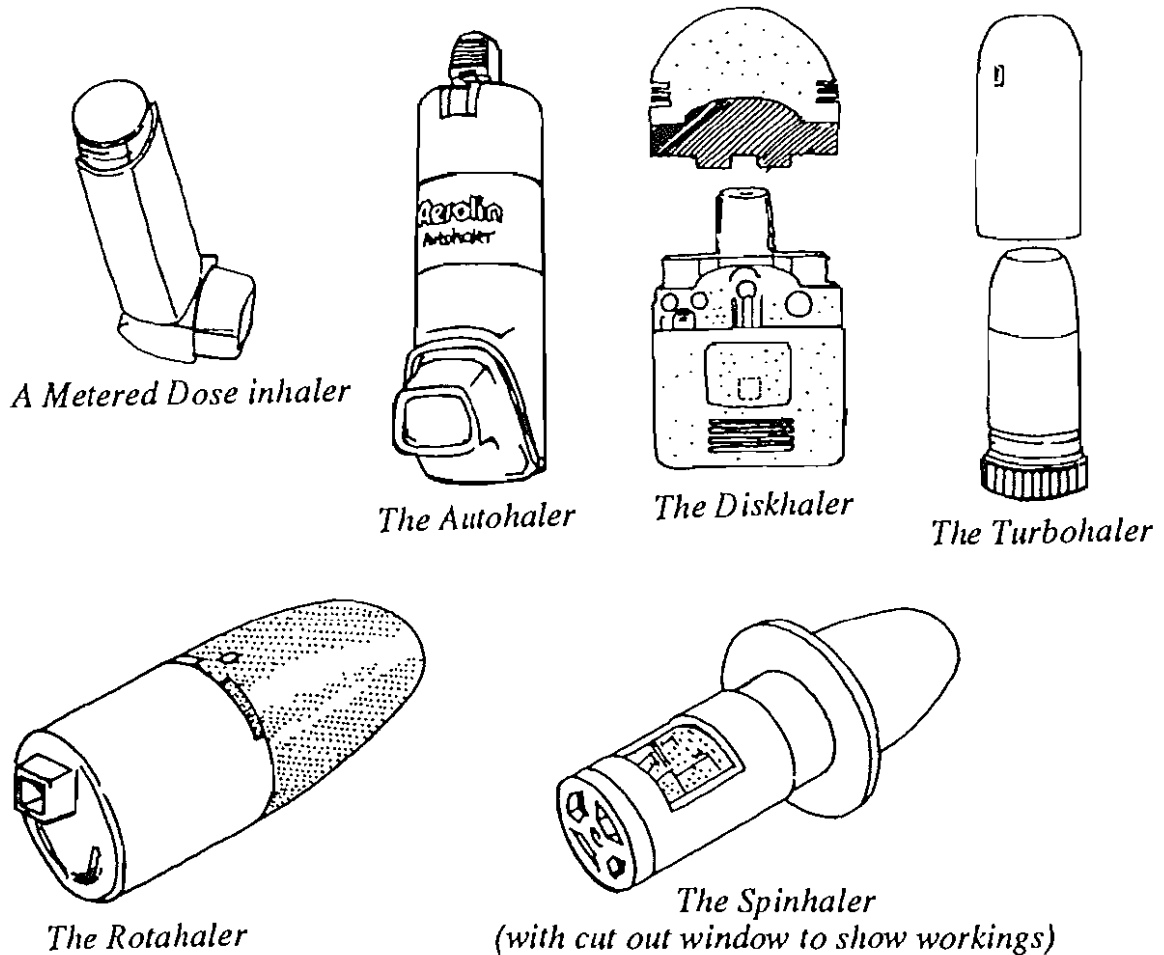


Figure 8: Some types of inhalers (pumps) used in New Zealand

Source: *Inhalers and things*, British Thoracic Society

(terbutaline). These are by far the most commonly used asthma drugs in New Zealand and are popular with asthmatics (and with doctors) because they usually produce rapid relief of symptoms in an acute attack. Beta agonists are usually taken from an inhaler (a pump). Some types of inhalers in common use are shown in Figure 8.

It is important to use the right technique with an inhaler, but this may be difficult to do in a bad attack. In this situation, an inhaler can be used together with a spacing device (see Figure 9) which holds the spray from an inhaler before it is breathed in. A more sophisticated (and expensive) device which has a similar function is a nebuliser

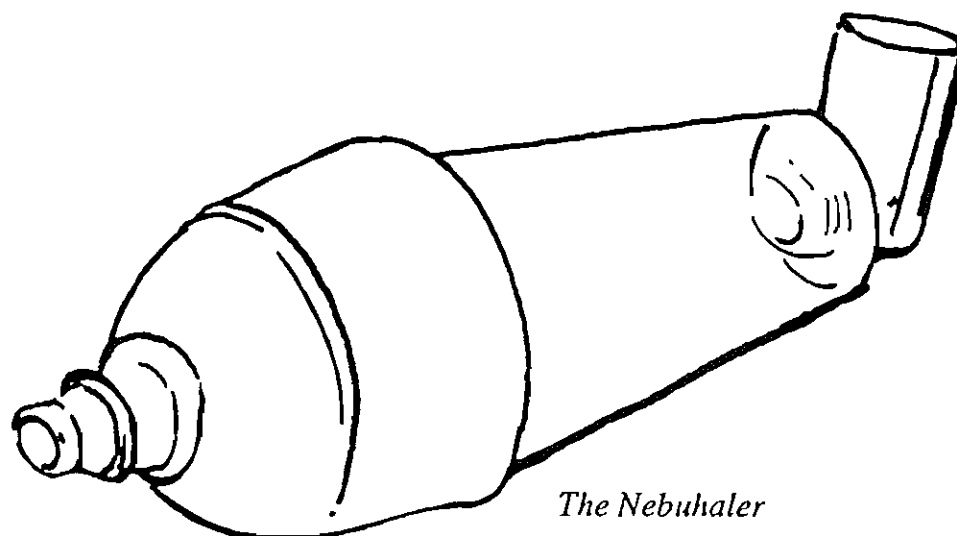


Figure 9: A spacer

Source: *Inhalers and things*, United Kingdom National Asthma Campaign

(see Figure 10). This has an electric pump, and delivers large doses of the drug. Many severe asthmatics have purchased nebulisers and keep them at home so they can take large doses of medicine in acute attacks. Nebulisers can be bought without a prescription, but the drugs which are used in the nebuliser can only be obtained with a doctor's prescription (as with other asthma drugs).

Beta agonists are usually effective in relieving the symptoms of asthma, and are popular for this reason. However, there are now some concerns about the safety of these drugs. In about 1979, doctors in New Zealand and other countries began recommending that asthmatics use beta agonists regularly (four times a day) rather than just using them to relieve symptoms in an acute attack. As a result, sales of beta agonists increased markedly,^[36] but the asthma death rate also increased in a number of countries.^[21] It is now feared that the regular use of beta agonists may actually make asthma worse in the long term.^[34] This has been shown conclusively with one beta agonist known as fenoterol (Berotec/Duovent) which is no longer used much in New Zealand.^[35] This problem may not be so bad with other beta agonists, but it could still occur. This is possibly the reason why the severity of asthma and asthma deaths has increased since beta



Figure 10: A nebuliser

Source: *Nebulisers in asthma*, New Zealand Asthma Foundation

agonists were introduced in the 1940s and 1950s. As a result, the role of the beta agonists in the management of asthma is currently being reassessed.^[63]

It should be stressed that beta agonists should be available to all people with asthma, and they will continue to play an important role, although in future they will be used less often than they are currently.

Although beta agonists can be life-saving drugs when used to treat severe asthma there are also concerns about the safety of beta agonists when used incorrectly in this situation. Firstly, beta agonists

are so effective at relieving symptoms, that they may create a false sense of security, and asthmatics may delay seeking medical help in a bad attack. In fact, many deaths occur because of such delays.^[53] A second problem is that some beta agonists which are no longer widely used in New Zealand, isoprenaline and fenoterol (Berotec/Duovent), may produce severe side effects on the heart. These could be dangerous in an acute attack, particularly if a person becomes short of oxygen. High dose isoprenaline caused an epidemic of asthma deaths in several countries in the 1960s,^[37] and fenoterol (Berotec/Duovent) caused a second epidemic of asthma deaths in New Zealand in the 1970s.^[38-41] Other beta agonists such as salbutamol (Ventolin and Respolin) and terbutaline (Bricanyl) do not have such serious side effects on the heart.

These concerns about the safety of beta agonists mean that it is important not to over-use them. They should be used for occasional relief of symptoms, or before exercise. Someone who is using their beta agonist inhaler regularly (several times a day) is in need of preventer drugs. Similarly, someone who has an acute attack should seek medical help immediately, rather than taking large doses from a reliever inhaler. In this regard, there is particular concern about the safety of the nebulisers, as they may create a false sense of security, and a person having a bad attack may not go to the doctor or the hospital until it is too late. Thus, while it is important that beta agonists are used to provide relief in a severe attack, it is also important to seek medical help and to obtain additional treatment.

Two other types of reliever asthma medicines should also be mentioned (see Table 2). Ipratropium bromide has no known side effects, but it is not particularly good at relieving symptoms. Theophyllines are widely used in some countries, eg the United States, and are safe and effective reliever drugs, although they may have some unpleasant side effects, particularly when taken together with beta agonists (see Table 2).

Preventer drugs

It is now believed that the inflammation of the tissue lining the airways is the most important problem in asthma. As a result, much more emphasis is being placed on reducing the inflammation, usually

by using two classes of drugs: corticosteroids and sodium cromoglycate (see Table 5). These drugs are known as preventers because they prevent asthma attacks from occurring if they are taken regularly. Table 5 shows some preventer medicines used in New

Table 5: Some preventer asthma medicines used in New Zealand

<i>Class</i>	<i>Brand names</i>	<i>Speed of action</i>	<i>Side effects</i>
Inhaled steroids	Aldecin Becotide Becloforte Pulmicort	Slow action, must be taken regularly	Do not usually cause the severe side effects which occur with oral steroids effects may still occur when used in high doses
Sodium cromoglycate	Intal Vicrom	Slow action, must be taken regularly	Throat irritation occasionally
Anti-histamines	Zasten	Slow action	Sleepiness
Oral steroids	Dexa-methasone Medrol Prednisone	Slow action (4-6 hours)	Mood change, increased appetite causing weight gain, swelling, bruising, bone damage. These serious side effects do usually occur with short courses (up to one month). Continuous courses may be required (despite the side effects) for troublesome asthma

Source: Adapted from *Asthma medicines in a nutshell*, Asthma Foundation of New Zealand

Zealand. The most common choice of preventer drugs are inhaled steroids, such as Becotide or Pulmicort, although Intal and Vicrom (see Table 5) are also often used, particularly by children. If control is still not obtained, then higher doses of inhaled steroids (such as Becloforte or high-dose Pulmicort) may be required. Preventers are usually sold in brown packaging in New Zealand, but this is not always the case and some preventers are sold in packaging of a different colour.

Preventers work slowly and need to be taken regularly. This is a major problem, because they do not provide the instant relief obtained with the relieving medicines. As a result, many people with asthma

do not bother to take their preventer medicines unless they feel sick, by which time it is usually too late. Therefore, it is important that asthmatics keep taking their preventer medicines, even if they feel well. Preventer drugs are usually taken by inhaler. Although there are some side effects with high doses of inhaled steroids (see Table 5), inhaled preventer drugs are generally safe, particularly if they are used in the minimum doses necessary to keep the asthma under control.

Although preventer drugs are usually inhaled, oral steroids are needed for severe asthma. Oral steroids are powerful agents for resolving an attack of asthma, but high doses can have severe side effects (see Table 5) when used for more than a month or so. Consequently, oral steroids are usually prescribed in short courses (one to three weeks), although long-term courses at a low dose may still be required (despite the side effects) for people with very bad asthma.

An action plan

The person who should be in charge of the management of asthma is the person who has asthma. Many people with asthma know little, and are told little, about their disease, and the management is left to doctors and other health care workers. This is quite different from the situation with some other chronic diseases, such as diabetes, in which patients usually know a great deal about their disease, and are shown how to manage it themselves. In recent years it has been increasingly recognised that this lack of patient education has caused many problems. In particular, an important factor in asthma deaths has been a delay in seeking help because the patient, relatives and doctors have failed to appreciate the need for emergency treatment. This is one reason why most asthma deaths occur at home or on the way to the doctor or the hospital,^[54] whereas few asthma deaths happen if people get to hospital in time.

The best tool for self-management is an action plan which can help someone with asthma keep it under control, and know what to do when the asthma gets worse. Although a number of rather complicated action plans are available, the best plans are those that are reasonably simple. Simple action plans work well, and have been found to be acceptable to people with asthma. One such simple action

plan, trialled in Britain,^[64] was found to improve asthma control substantially. People who followed the plan woke less often at night with asthma, had fewer days off work because of asthma, needed fewer asthma drugs, and had much better lung function. This plan has been printed on a 'credit card' and, together with a more detailed version, will be launched in New Zealand by the Asthma Foundation in 1992.

It should be stressed that this action plan is intended to be used by adults and teenagers, but is not particularly suitable for young children. Although some action plans are currently available for young children, these are relatively complicated; a simple plan for children is not available at this time. Nevertheless, it is important for young children and their parents or guardians to know when to seek medical help, particularly in an emergency.

The adult action plan

Table 6: An adult asthma action plan

<i>Step</i>	<i>Peak flow</i>	<i>Symptoms</i>	<i>Action</i>
1	80–100% of best	Asthma under control	Continue regular treatment and keep monitoring peak flows.
2	60–80% of best	Waking at night with asthma	Double the dose of preventer medicine (or start using preventer medicine if this has not already been done).
3	40–60% of best	Increasing breathlessness or poor response to reliever medicine	Start oral steroids (prednisone) and call the doctor (or nurse).
4	less than 40% of best	Severe attack	Call emergency doctor or ambulance

Source: Adapted from Beasley et al^[64] and the *Therapeutic Notes*^[59]

The adult action plan is presented in two versions, one on each side of the credit card (see Table 6 and Figure 11). One version is based on regular measurement of peak flows, whereas the other version is based on symptoms for those asthmatics who find it difficult to

ASTHMA ACTION PLAN

Name: _____ ISSUE DATE _____

		PEAK FLOW	▶	TREATMENT
1	BEST =		▶	Continue regular treatment
2	<80% =		▶	Double dose of:
3	<60% =		▶	Start prednisone & ring Doctor
4	<40% =		▶	Call emergency Dr or Dial 111 for ambulance

	SYMPTOMS	▶	TREATMENT
1	Asthma under control	▶	Continue regular treatment
2	Waking with asthma at night	▶	Double dose of:
3	Increasing breathlessness or poor response to	▶	Start prednisone & ring Doctor
4	Severe attack	▶	Call emergency Dr or Dial 111 for ambulance

Contact Dr: _____ Tel: _____

Figure 11: An asthma action plan available on a credit card

measure peak flows regularly. Although the version based on peak flows is preferable, there is some evidence that the simpler version based on symptoms may work just as well.^[65] The two versions are combined in Table 6.

Before the plan is started, the health care worker and the person

with asthma must determine the best obtainable peak flow reading. This is then used to determine the levels of peak flow at which the various actions will be taken. For example, if the best peak flow in a 30-year-old woman is 500, then 80% of the best peak flow corresponds to a reading of 400, 60% of the best peak flow is 300, and 40% of the best peak flow is 200. These values are then written on the credit card, and marked on the peak flow meter with a felt pen, to indicate the levels of step 1 (80%–100% = 400–500), step 2 (60%–80% = 300–400), step 3 (40%–60% = 200–300), and step 4 (below 40% = less than 200).

The action plan is then used as follows.

- Step 1: If the level of peak flow is at step 1 (80–100% of best), then the asthma is under control. Regular treatment, and regular monitoring of peak flows should continue.
- Step 2: If the peak flow is at step 2 (60–80% of best), then the dose of preventer medicine should be doubled (if the patient does not have a preventer inhaler then one should be introduced).
- Step 3: If the peak flow is at step 3 (40–60% of best), the asthmatic should start taking oral steroid (prednisone) tablets, and arrange to see the health care worker who looks after their asthma.
- Step 4: If the peak flow is at step 4, then a severe attack is occurring, or is about to occur, and the asthmatic should call the emergency doctor or the ambulance.

It should be stressed that the levels of 80%, 60% and 40% cited above are arbitrary, and that the asthmatic and the doctor may choose to use slightly different percentages.

The Wairarapa Maori asthma action plan project

The credit card plan has recently been tested in a study with Ngati Kahungunu in the Wairarapa. The test was conducted by Maori community health workers in partnership with asthma researchers at the Wellington School of Medicine. The Hauora Committee took the initiative in approaching Maori people in the district to gain accept-

ance and support of the research project by them and the Maori Executive, Wairarapa Tai Whenua o Te Runanganui o Ngati Kahungunu. The project was then launched with a series of hui at several marae in the Wairarapa, and marae-based asthma clinics were set up. These were organised by Maori community health workers, and by awhina huango at each marae.

At the clinics, people with asthma were shown how to use the credit card action plan, and this was followed up by further help from Maori community health workers. The people in the study kept asthma diaries to monitor the severity of their asthma. Asthma severity was checked for a two-month period prior to the introduction of the management plan, and over the four-month period following the introduction of the plan.

It was found that the use of the credit card plan lead to a significant improvement in the asthma of the people who took part in the study. In particular, their peak flows improved, they woke less often at night, and they had fewer 'days out of action' due to asthma. The participants commented very favourably on the programme. Everyone who took part in the final interviews thought that the marae-based clinics were 'good' or 'very good'. The main reasons for this were that the doctors were easy to talk to and explained things clearly, and that the marae-based clinic was more relaxed, friendly and informal. Participants also commented on the usefulness of the Asthma Action Plan credit card.

The findings were presented and discussed at a hui at Te Ore Ore marae in November 1991. The project used many of the methods that are recommended in this report, and it is therefore a very useful 'pilot project' for the recommendations in this review.

Discussion

In this chapter we have presented a brief overview of asthma management. There are many other factors which need to be considered in keeping asthma under control, and these need to be discussed with health care workers. However, following the simple rules outlined in the action plan can help keep asthma under control, and avoid severe attacks which may result in hospitalisation or death. The most important thing is that the person with asthma should be in charge and know

what to do. If he or she has control of the process, is motivated, has been well informed by health care workers, and knows what to do when the asthma gets worse, then asthma can usually be kept under control, and severe attacks kept to a minimum. If doctors and other health care workers are in control of the process, and the person with asthma is poorly informed, then problems and occasional disasters will occur, despite the best intentions of the health care workers concerned.



SECTION 3

Te mate huango e pa ana ki te iwi Maori

Asthma in Maori people



Te Ore Ore Marae – November 1991

CHAPTER 4

Access to health care

*Take the service to the people –
don't make the people fit
the service.*

Maraeroa – 8 October 1991

Summary

Access to health care is a problem for Maori people with asthma, and they are less likely than Pakeha to be prescribed preventer medicines. Major factors affecting access to health care are the cost and location of health services, the attitudes of health care workers and their communication skills, for example, the use of 'too many flash words'. These problems may emphasise feelings of whakamā and the reluctance to seek medical help. Many Maori people with asthma would prefer health services to have significant Maori management.

Access to health care is vital for people with asthma. Most asthma deaths in New Zealand occur between 8 pm and 8 am^[53] and in the weekends,^[66] when access to medical help is more difficult. Access to preventive treatment and health education is also important for keeping chronic asthma under control, and preventing acute attacks.

Access

Despite the large amount of research on asthma undertaken in New Zealand, there have been few studies of asthma among Maori, and the studies that have been done have often grouped New Zealand Maori and Tagata Pacifica (Pacific Islanders) together as Polynesians. These studies have generally found that access to health care and asthma education is poor for Maori people with asthma.^[67]

Studies in Auckland of reasons for ethnic differences in accident and emergency clinic attendance rates for asthma found that Maori and Pacific Islanders were less likely than Pakeha to have a regular general practitioner, less likely to be on preventive medications, less likely to have a crisis plan, and less likely to use a peak flow meter.^[68,69] Medication was found to be used inappropriately in all three ethnic groups. Relative to the perceived severity of their asthma, Maori and Pacific Islanders lost more time from work or school and needed to use hospital services more.

A further study in Auckland found that 33% of Polynesian children were not receiving any asthma drugs in the 24 hours prior to a hospital admission, compared with 14% of Europeans, and fewer Polynesian children were taking preventive medications.^[70] These differences were not explained by ethnic differences in the characteristics of the asthma.^[71] It was concluded that medical practitioners were making assumptions about the value of prescribing preventive medicines for Polynesians, and that this was an example of institutional racism.^[71]

A study in Hamilton found that the death rate for respiratory disease in Maori men was 3.5 times that for Pakeha men, but Maori men only visited a general practitioner for respiratory disease 1.4 times as frequently as Pakeha men.^[72] Thus, when the need for health care was taken into account, Maori men with respiratory disease were visiting their general practitioner less often than Pakeha men with respiratory disease. Among women, the death rate for Maori was 5.3 times that for Pakeha whereas the rate of general practitioner visits was only 2.1 times as great.^[73] The differences were not so great for asthma as for respiratory disease in general. Maori aged 15–64 visited the general practitioner for asthma about twice as often as Pakeha (Davis, 1987, unpublished data), but for children aged 0–14 years, the ratio was only 1.2 times. Overall, when the relative need for health care was taken into account, Maori people were visiting their general practitioner less often than Pakeha.

Compliance and self-management

Non-compliance with treatment may account for some of the Maori/Pakeha differences in asthma mortality and admissions.^[74] The term

'non-compliance' should be used with caution since it can be taken to imply that the fault lies with the patient, whereas it could lie with health care workers if the proposed treatment is inappropriate, too expensive, or inadequately explained. In this instance, the term 'non-compliance' refers to health care workers' non-compliance with patients' requests for help and information as much as it refers to patients' non-compliance with doctors' advice. Nevertheless, identifying differences in compliance is important in identifying potential causes of the high rates of illness and death from asthma in Maori people. Maori/Pakeha differences in compliance appear to mainly involve difficulties in seeking medical care when needed.^[67] Maori people often do not return for follow-up medical care at hospital-based asthma clinics, even though they use accident and emergency services more frequently than Pakeha.^[69,75] However, as noted above, it is important to emphasise that these problems of 'non-compliance' may indicate problems with the clinics as much as problems with individual patients.

Cost

A major factor affecting access to health care, which was cited in many submissions to the review committee, is the cost of going to the doctor. This includes the cost of travelling to the doctor's surgery, doctor's fees, and prescription charges. There are some sources of support available for people who cannot afford to pay for health care, including disability allowances from the Department of Social Welfare. However, of the people the review team spoke to, many did not know that these were available, or did not have the necessary social support and skills to make use of them. Similarly, some doctors were prepared to see patients who could not afford to pay, but many Maori people did not know that this was possible or were too *whakamā* to ask. Furthermore, there are also some general practitioners who are not willing to see patients for free, and this 'service' currently depends on the charity of individual general practitioners rather than being available by right. In these circumstances, it is not surprising that many Maori people do not take the risk of causing offence by asking for free treatment and instead avoid contact with the general practitioner altogether.

Prescription fees are also of concern. Until recently, these were generally less expensive than doctor's fees (unless the patient was taking many different medicines). However, prescription charges were increased in December 1990, and they are now a major barrier to health care for Maori asthmatics. Charges are waived once a patient has paid for a certain number of separate items within a year, but the initial charge may be enough to prevent people from being able to obtain their medication. Additional help is available for people with very low incomes, but these additional subsidies are offset by other cost increases.

A more specific problem was experienced in Wharekauri (the Chatham Islands), where medications can be obtained free from the hospital in Waitangi which is operated by the Canterbury Area Health Board. Virtually every asthmatic who spoke to the review panel on Wharekauri complained that they were having difficulties obtaining sufficient medicines from the hospital. In many instances, patients lived a long way from the hospital, but could only obtain one relieving inhaler (Ventolin) at a time, or sometimes only one between two persons because of restrictions imposed by the hospital (see Chapter 6). This caused considerable inconvenience and anxiety when the inhaler was unavailable, lost, damaged, or used up.

Strong support was expressed for low cost health clinics (such as union health clinics), and for the introduction of contracts for general practitioners by the previous Labour Government with the resulting lowering of fees. However, few doctors signed the contracts, and most general practitioner fees had remained the same or even increased despite the changes. Furthermore, the contract scheme has been scrapped by the new government and there is now even more uncertainty about the availability of affordable primary health care for low income earners. The 1991 budget increased subsidies for visits to the doctor and prescriptions for low income adults, but these positive moves may be offset by other changes (such as the abolition of the practice nurse subsidy) which will increase general practitioner costs. Furthermore, recent benefit cuts and increased unemployment have made it even more difficult for low income families to pay even small amounts for doctor visits and prescriptions.

Generally, strong support was expressed for the principle of free primary health care. A more specific suggestion was that chronic

asthmatics should receive a certain amount of free primary health care, eg six general practitioner visits per year, in the same way that primary health care is currently free during pregnancy.

Location of health services

The location of medical services was also frequently cited as a major factor affecting access to health care. Travel costs were cited by 22% of patients as a reason for non-attendance for follow-up at the free hospital-based chest clinic in a recent study at Middlemore Hospital.^[75] In general, costs of transport are more of a problem for people living in rural areas, but they are also a problem for some people with asthma who live in the city and who do not have cars.

Travel is a major problem in rural areas in terms of the time and inconvenience involved. In some rural areas, such as Wharekauri and the Mahia Peninsula, it can take one to three hours' drive on difficult roads to reach medical help. This makes it almost impossible to obtain help when a child has an asthma attack in the middle of the night. Often, the child may have recovered by the time he or she sees the doctor the next day, and this may make it difficult to get appropriate medical advice, or even to convince the doctor that the child actually has asthma.

Attitudes

On the other hand, it is apparent that costs of travel and doctor's fees are not the only factors which affect access to health care for Maori people with asthma. Some Maori people with asthma are reluctant to go to the doctor even to general practices that have low fees. The reasons for this are complex. However, there are indications that it is not sufficient for health care to simply be available; the health care which is available should be culturally appropriate.

One problem frequently cited in submissions was the attitude of many health care workers. An extreme case involved a general practitioner who had an egg-timer on his desk, and showed patients the door as soon as their time was up. Generally, many general practitioners did not have the time or even the inclination to help educate their patients about their asthma. Many patients had received no

instruction on how to take their medicines, and as a result some were using the wrong inhaler technique.

It should be stressed that in some areas (particularly Wellington) many asthmatics commented positively about their general practitioners (especially those in union health centres or other low cost centres), but the attitude of general practitioners was a major concern in most areas.

A further problem with general practitioners was that many of them apparently felt that they could manage their patients' asthma adequately by themselves, and were reluctant to refer patients on to hospital specialists. In several areas, no Maori person who spoke to the review panel even knew of the existence of asthma specialists. The reluctance of some general practitioners to refer patients to asthma specialists is of particular concern given the wide variety in knowledge of asthma among general practitioners. Many of them are excellent but some may not have kept track of recent developments in asthma treatment (such as the move away from reliever medicines and towards preventer medicines).

In particular, most people had not received any management plan for their asthma, and therefore did not know when to take their preventive inhalers and their relievers (or even which drug was which), and when to seek further medical help. Many patients stressed the need for a simple asthma management plan which would help them to manage their asthma themselves, and to know what to do in an emergency.

Consumer attitudes are also important in limiting access to appropriate health care. In a study at Middlemore Hospital,^[75] 36% of non-attenders simply 'forgot' their appointments. Such 'forgetfulness' can indicate a number of different deep-seated problems stemming from poverty, unemployment and racism, as well as other health problems. In such circumstances, it is not surprising that many patients do not realise the importance of follow-up when they are not currently troubled by their asthma.^[67] Furthermore, many patients who have had asthma for many years begin to regard their symptoms as 'normal', and become tolerant of a chronically low level of health. Such a tolerance to chronic asthma may foster indifference to acute asthma.^[66] As a result, any sudden deterioration in their already poor state of health

can rapidly bring them to the point where their asthma may become life-threatening.

Whakama

A powerful common statement at every hui attended by the review team explained more deep-seated problems of access to health care for Maori asthmatics: the experience of whakama. Whakama is a Maori collective or personal response associated with a broad series of Maori experiences. In Taranaki, Maori expressed whakama to the review team in terms of the raupatu, the definition of Maori as rebels, and the subsequent confiscation of lands. This pain runs very deep in Maori community memory and shapes attitudes toward the Pakeha who are frequently perceived as holding power and dispensing resources according to an uninformed and unsympathetic agenda.

Some dictionaries translate whakama into English as meaning 'shy', 'ashamed' or 'embarrassed'. Some Pakeha commentators have described whakama as involving not only shyness or shame for wrong-doing, but shame for being suspected of wrong-doing, embarrassment, feelings of injustice, powerlessness and frustration.^[77] Such feelings are not uncommon in Pakeha people, but can be particularly common and acute in Maori people, especially when confronting a health care system which shows little understanding of, or sympathy for, Maori cultural values and views of health. Whakama behaviour often involves withdrawal from communication with others, and yet it may stem from a wide range of feelings such as inadequacy, hurt or anger.

Combined with suppressed anger is the suspicion, common in colonised peoples, that Pakeha power means that the Pakeha way of doing things is somehow more valued and more real. This causes deep stress among Maori who may be comfortable and confident within Te Ao Maori (the Maori world) but experience acute discomfort when confronted with the sheer confidence and assumptions of reality which the Pakeha health system demonstrates. Powerful within its own culture, the health system can represent the epitome of Pakeha practice to a people subjected to a severe confidence crisis over the last 150 years.

Among Maori there is a strong element of self-blame for poor Maori health, while at the same time Maori acceptance of low health status as a norm is common.

This causes a range of responses among Maori people. Although some may challenge health workers, on the whole many Maori people prefer to contact the health service as little as possible. Maori are also extremely protective of their Maoriness while in contact with Pakeha, often preferring to behave in a restrained and self-protective way in order to confine the interaction to 'safe' activity. Their behaviour tends to be interpreted as passive, when in fact it is protective. For Maori, the attitudes of these health professionals are part of a lifetime of being treated in a negative way by school teachers, shopworkers, DSW workers, nurses, doctors, bosses and authority figures in Pakeha/Maori contact.

Whakama was expressed to the review team in a variety of ways.

'I feel the doctor and nurses are judging me for not looking after my baby properly.'

'Am I responsible for my child's asthma? Have I created it?'

'That clinic is for Pakeha people.'

'The doctor doesn't listen to me when I tell him my baby has asthma.'

Comments such as these were common during formal oral submissions to the review team and informal discussion.

These problems are often even more severe when Maori people are admitted to hospital, because of the lack of consideration for Maori cultural values which is still evident in most New Zealand hospitals. For example, many Maori people are extremely distressed at having to eat, sleep and carry out ablutions in the same bed, and for this reason alone are reluctant to stay in hospital. Once again, conscious or unconscious attitudes of doctors or other health care workers may emphasise the feelings of whakama, and the reluctance to seek medical help in future.

The message and the messenger, and mediators

Many Maori discussed the difficulties encountered in discussion of asthma with health professionals. To sum up 'they use too many flash

words'. This is not an indication to health workers to modify their medical terminology or to learn to speak the specific dialects of English used by many Maori people. Rather, it is likely to be more successful to train Maori people who already communicate in a manner which is useful and acceptable to other Maori people.

A consistent theme at each hui was that Maori people would prefer their education and service delivery to come from Maori. In particular, many Maori people expressed a preference, if given the choice, for marae-based health services. It was also stressed, however, that being located on a marae was not enough in itself. In fact, one marae-based asthma clinic received considerable criticism because it still operated like other asthma clinics apart from its change of location.

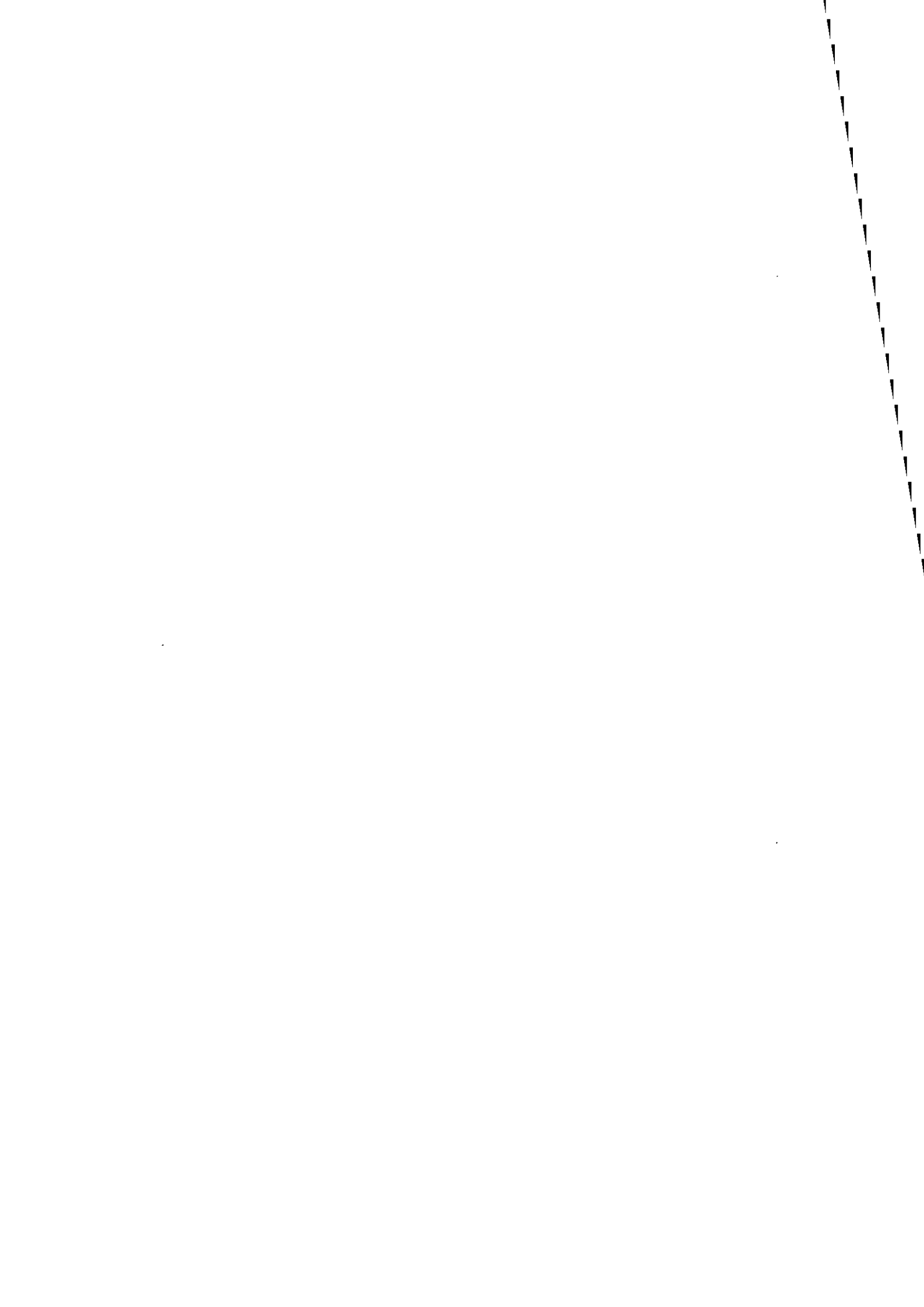
What was considered more important was that the attitudes of the health care workers should change, and that decision-making power should also move into the community along with the clinic itself. Thus, such clinics should have significant Maori management. A related issue was that many Maori people preferred to see Maori doctors and nurses if they were available. A further, and perhaps more important, advantage of marae-based health services is that they permit culturally acceptable asthma education to be carried out by Maori community health workers both on and off the marae.

Discussion

In summary, the factors affecting access to appropriate health care and health education for Maori people with asthma are complex. The cost of health care is clearly a major problem, and strong support was expressed for moves to reduce the costs of general practitioner visits. However, it was also clear that cost was not the only problem, and that many other changes are required. In particular, there is a clear need for greater patient education about asthma, and the introduction and use of simple management plans. Although some general practitioners do make the effort to educate people about their asthma, general practitioners are not trained for such work and are not always good at explaining such concepts in plain language. Furthermore, the fee-for-service system inevitably limits the amount of time which general practitioners are prepared to spend on patient education. Thus, most asthma education will continue, and should continue, to be done

by practice nurses, community health workers, and specialist asthma educators. The need for asthma educators who are Maori emerged as a clear issue.

Generally, a number of different aspects of doctor and patient attitudes combine to discourage Maori patients from seeking medical help for their asthma. In particular, this means that Maori patients are often reluctant to return for follow-up when their asthma is stable, but instead tend to wait until a crisis occurs before seeking medical help. Much can undoubtedly be done to improve the situation by encouraging greater understanding of and consideration for Maori cultural values on the part of health care workers. However, strong support was also expressed for more innovative approaches, including culturally appropriate marae-based health services.





Health workers at Te Ore Ore Marae – November 1991

CHAPTER 5

Asthma education

Doctors need to be educated.

Kohupatiki Marae – 27 September 1990

Summary

People want to take charge of their own health. They want to know more about asthma and what they can do for themselves, but there are difficulties in the approach used by health professionals when communicating with Maori people about asthma. The key role is that of the Maori asthma resource person, who can act as a buffer between the existing health services and Maori people, provide asthma information on a continuing basis, and develop an asthma support system for the whanau.

Hoatu he ika ki te tangata
Kua whiwhi ia i te kai
Akona te tangata ki te hi ika
Kua whiwhi ia i te oranga tonutanga.

*Give a man a fish and you give him a meal,
teach him how to fish and he will live forever.*

Wairoa, 26 September 1990

In every area we visited it was clear that the greatest need for improved health is information. People are desperate for knowledge about asthma, practical knowledge which will help them live free from anxiety and the fear of dying. They want help to be lifted from a state of depressed hopelessness and despair, and a possible lifespan which may not exceed 50 years.

The review team learned of the extremes in awareness of the cause and management of asthma among Maori from people attending the hui. In many places asthma was managed effectively in extremely trying circumstances, such as the isolation of Wharekauri (the Chatham Islands) where restricted access to medication was evident.

The desire to achieve self-determination and take responsibility for their own health was obvious among people in every community visited by the team. It was also clear in some places that effective teaching had occurred, but this was the exception rather than the rule.

The people the review team talked with want to take charge of their own health; they want to know what they can do for themselves. They want to talk to someone about why they have asthma, where it comes from and what to do about it. Few people understood the first signs and symptoms and accepted a cough and runny nose as a regular part of Maori life. It was clear that there was a difficulty in the educational process currently used by health professionals when communicating with Maori about asthma. Many basic questions about asthma were asked at every hui; reflecting the skills of the teacher rather than the inadequacy of the learner.

When asthma got worse, a visit to hospital emergency services was a visit to an unfamiliar environment with unfamiliar routines which exacerbated feelings of whakama, producing a sense of suspicion and mistrust of the system, the treatment and the caregivers. Patients told us the kind of medical treatment they get is out of step with Maori lifestyle. The sensitivity of whakama means important questions about asthma will not be asked, which may indicate to Pakeha that knowledge is already there, 'when you don't ask you must know'.

The Maori way is to talk about things and to take time to talk about them. The people we met do want to know about choices for getting well. The regular medical management tends to be narrow, clinical and not enough on its own. Maori people are wary of medicines. They are not told how they work, what they do or even if they have side effects. We heard numerous accounts of inhalers which were puffed into the air and never actually breathed in at all, because the general practitioner had not taken the time to explain how to use the device correctly.

The need for a Maori asthma resource person

Maori people are looking for answers and during the review process the team could see an answer to improved asthma management emerging – the need for a Maori asthma resource person. The name is convenient for this document but other suitable terms could be applied. The issue is what this person's role would be. It must be emphasised that registered nurse training, teacher status or medical qualifications are not envisaged as being necessary for this job.

What must be recognised is the need to pass on information the moment someone needs it – not at the five minute appointment next week or at the time of the emergency hospital admission. The time when people require information is when they ask for it. There needs to be a buffer between existing health services and Maori people – a person who can liaise with both camps – a Maori person.

In many places the review team visited, this person is already there, either formally or informally. The strength of Maori society is the positive support system and the framework which is often already in place to conduct health education. Within each whanau people are respected for their life experiences, including the kuia and kaumatua, who show commonsense, understanding, compassion and sincerity. These people take time to talk, can be contacted readily, are accessible at night or in the weekends and demand no fees. They are acquainted with the complexities of social order in the community and are sensitive to the special needs of the people. They are often aware of any underlying problems and related difficulties not usually apparent to outsiders. Above all they are an accepted and established part of community life, whereas the outside Pakeha who is not aware of these subtleties is not truly accepted. No matter how much knowledge the Pakeha caregiver holds, if they are not an acceptable messenger, the attempt at health improvement will fail.

In the far north the review team heard of a good system already in existence, Te Ringa Atawhai. This group has 61 Maori health workers operating with little funding on the exact basis we recommend. In Wanganui there is a similar group, Te Korimako Maori Health Committee, also enormously successful, using these methods. In the

Wairarapa a group of Maori health workers working in partnership with Pakeha health care workers is also achieving success in asthma education and management among Maori people through a system of marae-based health clinics and the use of a simple management plan (see Chapter 3).

There are also Maori health professionals doing asthma work along with other work of major importance to Maori health. These people are doing a superb job but they are few in number and covering a broad area.

The review team also noted a number of community people who have had professional health training, but are no longer in the workforce. Such people may be interested in becoming Maori asthma resource persons to utilise their skills and expertise.

In isolated areas like Wharekauri (the Chatham Islands) and the Mahia Peninsula, while there is no Maori resource person at the moment, filling this role is easily achievable. The existing network systems are stronger and more easily developed in the rural areas. However, suburban support groups, while more difficult to establish because of the fragmented nature of urban communities, must be instigated.

Training of Maori asthma resource persons

The Department of Health, Regional Health Authorities and the Asthma Foundation have a responsibility to provide funding and training for Maori asthma resource persons to deliver knowledge and skills that may be easily passed on to the whanau. The content of such training may include the following topics:

- importance of karakia in the healing process and the interweaving of Maori values;
- basic asthma knowledge as standardised through Asthma Foundation publications;
- basic general knowledge of parts of the body, particularly the chest, and how the lungs work;
- factors that make asthma worse – eg animals, bedding, dust, smoking;
- importance of stress-related difficulties – eg unemployment, housing, relationships, education;

- access to health networks – general practitioners, specialists, social workers, Department of Social Welfare, chemists, teachers, public health, practice nurses, asthma society;
- complementary medicines, their place in the treatment of asthma;
- basic knowledge of medication;
- management plans;
- thorough knowledge of inhalers, how they work, what they do, maintenance, cleaning and side effects;
- nebulisers, where to get them, cost, options available, servicing;
- importance of diet, sleep and exercise.

Training for Maori asthma resource persons would best be organised by a Maori asthma committee in the Asthma Foundation on a regional basis and conducted on marae with some work being covered through correspondence. These resource people would be encouraged to attend local training days on specific topics. Training should be continuous to update changing methods and current thinking, perhaps bi-annually.

The review team sees an important role for Maori asthma resource people providing asthma information on a continuing basis, setting up and providing an asthma support system for the whanau, having knowledge of existing local health networks, being accessible and inexpensive. The team also recognises at the same time that such resource workers do not replace medical advice, neither do they give it, but they could provide a link between the community and medical practitioners.

Educational resources

Some areas of asthma education can be introduced in Te Kohanga Reo using breathing games and exercises, for example. Some waiata lend themselves to controlled breathing techniques and there is room for imaginative and exciting material to be produced.

The poi, haka and taiaha require the development of techniques for better breathing and this can be utilised to improve health. This could be an easy way to start educating young Maori people about asthma, particularly young Maori males whose knowledge about asthma is often low.

Videos using local people, kaumatua and others, to get the message

across in an appropriate and acceptable manner could be valuable as a means of educating in a relaxed environment. They could be made professionally with the assistance of the Maori Asthma Committee without spending a great deal of money. Their greatest advantage would be the use of local surroundings and people.

Appropriate resources could be developed by modifying some material already in use. Asthma support groups could be encouraged to produce charts and posters using their own creative resources.

Funding of Maori asthma resource persons

Regional Health Authorities have a responsibility to this neglected area of community health and should recognise that Maori health can improve if health initiatives have significant Maori management and significant community input. Asthma self-management, is well behind diabetic self-management which has been operating for 20 years. Asthma could be dealt with effectively in the Maori community through funds provided at flax-roots level to community health initiatives which would allow the Maori people to help themselves.

Finances spent in this area would most certainly result in the following benefits:

- help prevent further asthma deaths;
- keep people out of hospital, thereby reducing costs;
- improve quality of life;
- stimulate a positive outlook through providing a focus on wellness;
- reduce days lost at school;
- reduce family stress by providing specialist knowledge on asthma management;
- through improved management, reduce health care spending on medication due to wastage and misuse.

A Maori asthma resource person position should be implemented as soon as possible in each of the 10–15 major districts in New Zealand, and training and resources made available to groups in all areas (the districts could be defined along the lines of the old 14 area health board boundaries, or some similar division).

SECTION 4

He tirohanga whanui

The review process



Kirihaehae Marae – October 1990

CHAPTER 6

The review process

*Too expensive – one-year-old baby,
three visits – \$30,000. No transport.
No phone.*

Maraeroa – 8 October 1991

The Hon Koro Wetere, former Minister of Maori Affairs, asked for a review of asthma in Maori people in 1989 after concerns were expressed by the Asthma Foundation. It was noted that there was an excessive number of deaths from asthma among Maori people and many required hospital treatment even though current evidence suggested asthma was no more common in Maori than Pakeha. There had also been suggestions that there were serious problems in the management of asthma in Maori people, major difficulties in getting expert help when needed, and a serious lack of meaningful and clear information about asthma that was readily available to Maori asthma sufferers.

Under the Chairmanship of Professor Eru Pomare, Professor of Medicine at the Wellington School of Medicine, a small review team was established. The other members of the team were Mr Hohua Tutengaehe, QSM (kaumatua, Christchurch); Mrs Makere Hight (Asthma Education Officer and Asthma Foundation member, Auckland); Mrs Irihapeti Ramsden (Nursing Adviser, Wellington); and Dr Neil Pearce (Epidemiologist, Wellington). Secretarial and administrative assistance to the review team was provided by Ms Vera Ormsby from the Maori Health Unit, Department of Health. The review team first met on 28 May 1990 and the terms of reference for the review and a preliminary itinerary were agreed upon. In essence the Minister of Maori Affairs wished to be advised about all aspects of asthma affecting Maori people but in particular for the review team

to prepare something practical for Maori people on asthma management and to highlight problems and make suggestions about access to health care. In order to accomplish its task the review team has researched current knowledge on the extent and consequences of asthma in the Maori community in addition to receiving many written and oral submissions.

To promote the kaupapa of the asthma review, advertisements calling for written and oral submissions were placed in regional and national newspapers and members of the review team were interviewed by local radio stations and newspapers. Various hui were held throughout New Zealand and organised so as to hear views from both urban and rural Maori and those who were geographically isolated. More visits were planned in the northern parts of New Zealand where the greatest number of Maori people live. Maori people were the major participants at these hui and most were either asthma sufferers themselves or they had asthmatics in their whanau. A few general practitioners and asthma specialists also attended the hui.

It is not surprising that the majority of the submissions on asthma in Maori people highlighted problem areas as opposed to good things that were happening. Much criticism was levelled at general practitioners, yet few doctors attended the hui or made submissions. This is an important area which needs further exploration.

While the nature of this review does not allow us to quantify the true extent of asthma problems among Maori people, the experiences reported to us during our review were real, at times terrible. Such experiences lead us to believe much work is needed if asthma management in Maori people is to be improved and deaths avoided.

Asthma review hui

Te Rehua Marae, Christchurch – 14 September 1990

Approximately 25 people attended, the majority being Maori who were either asthmatics or had whanau members who were asthmatic. An asthma specialist from the Canterbury Area Health Board was present.

Major concerns were expressed about the lack of effective asthma

education/information. There were concerns about all aspects of asthma including the nature of the condition itself, its management and the use of medication and peak flow meters. There were considerable anxieties about when to call the doctor and knowing when the problem was serious.

It was reported that written communication was ineffective. Many Maori could neither read nor write. It was suggested that the most effective communication was oral and through the use of television or video material. There was a need for Maori people to participate in the preparation of educational/information materials and be seen to 'deliver the goods'. Much of the information about asthma and its management was gained informally through family contacts or close friends who compared notes about their asthma and its treatment.

None of the asthmatics present knew that there were chest specialists from whom a second opinion could be sought. A specialist chest physician in attendance was amazed that none of the asthmatics present (some severe) had ever been seen by a specialist. It was clear that for Maori people, the GP was the major manager of asthma whatever its severity. It was suggested during the discussion that Maori people were not assertive enough when dealing with health professionals. However, it was emphasised that it was not the role of Maori people to question the mana of the doctor and his/her ability to manage their asthma because he/she was the expert.

Major problems with cost of medical care were highlighted. These costs included not only consultation fees but also costs of medication and transport. Few Maori had dealt with doctors who would waive their charges. This seemed contrary to the general view expressed by general practitioners that they commonly did not charge.

None of the Maori participants was aware of the existence of the Asthma Society. There was a strong call for a simple asthma management protocol, particularly for use in severe attacks. Many questions were asked about the interpretation of different symptoms and how one would know that the problem was serious. Many at the hui supported the idea of setting up a support group in asthma. Those who attended felt that the hui had been a very worthwhile exercise as they had learned a lot about asthma from each other.

Murihiku Marae, Invercargill – September 14 1990

There were approximately 20 participants at the hui and again, many of the questions asked and the responses to our enquiries were similar to those encountered at Christchurch earlier in the day.

Particularly important was the relationship between the Maori asthmatic and doctor. It was quite clear that Maori asthmatics, even if dissatisfied with treatment, felt unable to question the integrity of the doctor in his or her management. This meant that only one person with asthma at the hui had ever been to a specialist clinic and this visit was a result of admission to hospital with a severe asthma attack. He was seen by a specialist and referred back to his doctor. Although he was unhappy about his treatment he felt he could not question his doctor's management. This situation represents an important cultural aspect in the doctor/patient relationship which may inhibit optimal management of asthma.

Cost of consultation with a doctor was again highlighted as a major problem relating to access to health care. There was considerable concern about the recognition of severe asthma which required emergency treatment. Many Maori were reluctant to call their doctors unless it was really necessary and this usually meant life-threatening asthma. More guidance and information about asthma management was felt necessary. Asthma Society members present felt as a Society they had tried hard to involve Maori people in their asthma seminars but had been disappointed that few Maori people availed themselves of what they had to offer. Few Maori however were aware of the existence of the Asthma Society and its kaupapa.

*Chatham Islands – 17–20 September 1990**Whaka-Maharatanga Marae, Te One – 17 September 1990*

Approximately 30 people attended the hui. Many questions were asked about specific aspects of asthma management. Some people expressed considerable dissatisfaction with the management of their asthma over a period of years as they had seen little improvement using current medications. Many people had only beta agonists while others borrowed different forms of medication.

There seemed to be little education/information about asthma and there was some confusion about what asthma actually was. Few

people had heard of peak flow meters although one person had brought his back from the mainland. Dissatisfaction with their doctor and his management of asthma was mentioned but there was a reluctance to complain – ‘it was better to keep quiet than make a fuss’ – as this could make the situation worse. Many patients wanted to get a second opinion about their asthma but this was obviously difficult because of the cost of visiting the mainland. It was unlikely that a specialist would visit Wharekauri, but many thought that specialist visits would be very helpful indeed.

Concern was expressed at the difficulty in gauging the severity of asthma and there was also concern at the availability of certain medicines. For instance, one patient had stocked up on six months’ supply of Ventodisks as these seemed to be rationed on the Chathams. One death due to asthma was mentioned.

Hui at Colleen Butterfield's home, Kaingaroa

This was a small but nevertheless valuable hui in which three families of asthma sufferers were present. The major problems were those of extreme isolation. Kaingaroa was at least an hour’s drive from medical help at Waitangi. For one family the trip to Waitangi took between two and three hours of driving across swamps, through a lake and over uncharted tracks. This mother had two young asthmatics, both of whom had had severe life-threatening episodes of asthma. However, since starting Becotide five weeks previously there had been a dramatic improvement in the condition of both children with peak flow measurements being normal, night cough disappearing and general level of wellness much improved.

There was some dissatisfaction with the Chathams doctor but by being assertive, one of the mothers was able to improve the management of her children. Having a supply of prednisone for emergency episodes was extremely useful and had eased anxieties. There was also criticism about apparent rationing of asthma inhalers. On one occasion a child’s inhaler was smashed by being run over in a car and this produced extreme anxiety for both the mother and child. This anxiety was not alleviated until an inhaler was borrowed from another asthmatic an hour or so away. It seems that when inhalers are lost, misplaced or broken it is difficult to get a replacement. Patients asked why they could not have several inhalers to help in emergency

situations. The sharing of inhalers was also felt to be unhygienic, yet some people were forced to share. The need for specialist opinions about asthma was mentioned and a large number of questions were asked about asthma itself and its management.

School dental clinic, Te One – 18 September 1990

Professor Pomare held a clinic to allow patients with asthma to see him privately. Eight patients were seen, all of whom had asthma and a variety of other complaints. With respect to asthma, two severe asthmatics expressed considerable concern about adequate supplies of medication. They also complained, as others had, about having to share inhalers. One patient said that he 'nearly died' because he wasn't able to get medication. Another patient said he had wheezed for several years but was afraid to go to the doctor in case the doctor told him he had asthma. The nature of his asthma was explained to him (he was wheezing at the time) and he was told that it was important for him to report to the doctor. Another patient reported difficulty in getting an inhaler and said that it was easier to get these through the hospital nurses.

Evening public meeting, Waitangi Hall – 18 September 1990

The public meeting was preceded by a talk-back show on Radio Weka with Professor Eru Pomare. The interview included many questions about asthma, the review team and results of the review to date.

About 30 people attended the public meeting. There was a considerable amount of questioning about asthma and its management and concern was expressed, yet again, about supplies of asthma medications. The hospital policy of limiting each patient to one inhaler, and people having to share medications was criticised. There was frustration and anger expressed by some at the management of their asthma and issued another call for specialist visits. There was also considerable support for the idea of an asthma support group, which was strongly supported by the County Chairman.

Owenga School, Owenga – 19 September 1990

Owenga School has 10 pupils and two teachers. At the time of our visit there were no known asthma sufferers at the school. However, the difficulties associated with one asthma sufferer the previous year

were outlined. In particular, the child's mother did not allow the child to have an inhaler at school for fear of over-use by the child. This provoked considerable anxiety and wheezing episodes by the child which necessitated visits home to get treatment and this was a great source of frustration to the teachers. The problem remained unresolved. The school teachers felt they had an important role to play in the welfare of any child with asthma but this was made very difficult by not having the requisite medications at school with the child.

Discussion with resident Chatham Island doctor – Dr Paul Helliwell at Waitangi Hospital – 19 September 1990

Dr Helliwell expressed frustration at not being able to provide as good a service as he would have wished to patients on the Chathams. This included not being able to send more patients for second opinions to New Zealand and not being able to get adequate supplies of medicines. He felt his job was frustrated by restrictive policies from the Canterbury Area Health Board concerning the transfer of patients with significant illness to Christchurch.

With respect to asthma, he was frustrated that many of his patients failed to keep appointments, did not come back to see him as frequently as he would like, and if they did come it was only to pick up a further prescription for medication. I asked him about his policy of limiting the distribution of Ventolin inhalers to asthma patients and his reasons for this were firstly to protect a limited resource and secondly to encourage his patients to visit him more frequently to pick up their medication. I told him of the concern of many patients that they felt very vulnerable should they lose or run out of their inhalers and were not able to get one reasonably quickly. Dr Helliwell mentioned some problems in getting supplies of medication to the Chathams, such as the inhaled steroids and this has limited his ability to treat asthma on occasions.

Evening meeting with members of the St John Ambulance team, at the Chathams Lodge – 19 September 1990

Four members of the St John Ambulance Team attended this meeting and they were particularly interested in aspects of asthma education

and the emergency care of severe asthmatic attacks. They were supportive of an asthma support group being formed on the Chathams and believed that their group could be the focus of such a support group. One member of the team, a registered nurse, reiterated Dr Helliwell's previously mentioned frustration about not being able to transfer patients to New Zealand, or to get specialists to see patients, or for specialists to visit the Chathams. There were problems with the delivery of medicines to the Chathams so that there were occasions when the vital medicines, although ordered, had not arrived. It was also mentioned that difficulties were experienced on the Chathams with doctors who did not speak English very well or who stayed for only a short time.

County Court, Waitangi – 20 September 1990

Eight people with asthma were seen. Two of these had never been seen by a doctor but had been treated by their parents who were also asthmatic. Asthma medications were shared. There also seemed to be a general reluctance by these asthmatics to use the hospital system, one of the major reasons being the hassle of having to travel considerable distances. During this clinic I answered many questions about asthma and it was clear there was a strong need for more information and educational advice. These asthma patients mainly came to see me because they all wanted a second opinion about their problem.

*Meeting at Whaka-Maharatanga Marae, Te One –
20 September 1990*

Approximately 20-30 people attended this hui. A general discussion with the public about our Chathams visit and its accomplishments took place. There seemed to be general enthusiasm not only about the visit itself but especially for the idea of setting up an asthma support group, perhaps in conjunction with the Asthma Society. It was hoped that continuing discussions could occur with Margaret Hight liaising with the local people. The County Chairman, Bunty Preece, donated a sum of money to initiate the setting up of a support group.

The major problems with asthma on the Chathams seemed to centre around difficulties with follow-up: difficulty of referral to specialists, rationing of medications and medications running out, lack of

education about asthma, widespread smoking, and patients being less assertive with the doctor than perhaps they should be. Along with the enthusiastic support for setting up an asthma support group there was also a strong plea for visits from specialist medical people to the Chathams.

Kohupatiki Marae, Clive – 27 September 1990

Approximately 15 people attended, the majority being Maori who were asthmatic or had family members who were asthmatic. As at previous hui there were many questions asked about asthma and its treatment and this pointed to the great need for more information and relevant educational materials about asthma within the Maori community. Money problems were again mentioned, particularly the cost of GP visits, the cost of transport to the doctor and the cost of medications. The high cost associated with emergency assistance, especially at night, was highlighted and regarded as a serious disincentive to seeking help. One participant at the hui had health insurance.

The role of pharmaceutical companies in the doctor's management of asthma was raised by a Maori asthmatic. This patient had noted that his doctor's prescribing habits were influenced by incentives offered by pharmaceutical companies. This created considerable stress for this patient who had been responding well to certain medications but because of new medications that had come along and which were being promoted by a pharmaceutical company, his medications were changed. The patient felt like 'a guinea pig' on the new medication. Another problem relating to medication in a different patient related to lack of effect of the drug. The patient felt embarrassed about returning to the doctor because her non-improvement might be perceived by the doctor as a case of non-compliance.

Chemical spraying of orchards was regarded as being hazardous for some asthmatics. The question of smoking was also a big concern, whether this meant smoking by asthmatics themselves or inhaling second-hand smoke of others.

The idea of an asthma support group for the area was raised and supported. It was also felt that consideration should be given to the establishment of an alternative referral system for Maori patients seeking a second opinion about their asthma as it was a rare event for any of the asthmatics to be referred for a specialist opinion. It was

also felt that schools needed to be better equipped with medications and educational information about asthma. In addition it was suggested that Maori asthmatics be employed to deliver asthma education messages, perhaps on a one-to-one basis – ‘kanohi ki te kanohi’. Finally it was noted that at the Napier Hospital Children’s Ward there was a list of the names of asthmatic children in the area.

*Hui at the office of Taiwhenua o Ngati Kahungunu, Wairoa –
27 September 1990*

Approximately 35 people attended this hui. Participants were from rural, isolated areas such as Mahia and Nuhaka about 45–50 miles northeast of Wairoa, Waikaremoana 50–55 miles northwest and Raupunga 30 miles south of Wairoa.

The principal concerns were those highlighted at previous hui and included the lack of information and appropriate educational material about asthma, and problems with accessing health care, which in many instances was compounded by the geographic isolation of some families. Indeed in some areas vast distances had to be travelled to get to health services and it was suggested that mobile or community-based services be established.

Wairoa has considerable social problems not the least of these being high unemployment. Major cost barriers therefore exist in accessing health services. Concern was also expressed by some participants that there was discrimination within the services when it came to getting nebulisers. An example was provided of an assertive non-Maori asthmatic living in a rural area getting a nebuliser when a Maori in a similar isolated rural area could not get one. The concept of whakama was raised and it was also highlighted that many Maori patients would not question the advice of their doctor – ‘he was the expert’. A strong plug was made for the promulgation of a simple management plan for asthma and for the training of Maori asthma educators.

It was also mentioned that there were literacy problems with Maori people and therefore there was a need for educational material for Maori people to be carefully prepared. The use of video was mentioned. It was also noted that many health professionals used medical jargon which was not easy for patients to understand. There was a plea for more simple language to be used and for doctors to spend

more time explaining problems. There was a need for visiting specialists to come to Wairoa but because of resource problems these visits were irregular.

Finally, one of the people had noted that when the ewes were in season at Mahia, asthma seemed to be more common. Chemical spraying and smoking too were highlighted as major aggravants of asthma in the area.

Rere School, Matawai – 28 September 1990

This was a brief unannounced visit to this small school some 40-50 km inland from Gisborne. Of the 10 children present, three were asthmatic. The school teacher and pupils seemed to be comfortable with the management of asthma should problems arise at school.

Waioeka Marae, Opotiki – 28 September 1990

Approximately 20 people attended, people coming from as far as Tauranga, the East Cape and Whakatane. Many of these people were asthmatic.

The major concerns expressed at this hui related to access to health care and this was as much a problem of cost as a problem of transport. The district nurse system was mentioned as being helpful as was the rapid admission of asthmatics to Opotiki Hospital in times of need. Considerable concern was expressed at the role that agricultural sprays, pollens and smoking played in precipitating or aggravating asthma. One participant from Mangakino said that pollen from pine trees exacerbated her asthma terribly but she was not able to move from the area for socio-economic reasons. Others mentioned the deleterious effects of pine pollen.

The whole question of asthma education and information was raised and one of the kuia who had suffered life-long asthma described how she had taught her children and mokopuna to use medications properly and to carry out basic physiotherapy, such as postural drainage and breathing exercises. She also felt that she had an important role as an asthma educator for her whanau and she also believed strongly that patients could be much more assertive with their doctors once empowered with information.

The concept of whakama was raised and cited as an important

barrier for some to health care. The use of Rongoa Maori was discussed and in particular it was noted that kawakawa relieves breathing distress and kumara hou loosens phlegm. The idea of an asthma support group was raised as a means of sharing information and knowledge about asthma and for lobbying for resources for asthma.

Tunohopu Marae, Rotorua – 28 September 1990

Approximately 30 people attended this hui from as far afield as Te Puke, Murupara and Kawerau.

The major concerns raised at previous hui were again discussed, including the lack of good asthma information, the problems with getting medical care because of costs and the need for a simple management plan.

'Panic' accelerates the severity of asthma and there is a need to know what to do in a crisis. The lack of appropriate information – 'what to do, where to go' – was a problem for many. It was also mentioned that many people who have asthma, especially children, remain undiagnosed. There was some criticism of the ability of some doctors to communicate adequately with their patients and it was felt that doctors needed training, not only in communication but also in asthma management. Four recent deaths from asthma were discussed, and again the pollen from pine trees was mentioned as a major problem for asthmatics in the area. In Murupara there was a serious problem of unemployment which meant visits to the doctor were less likely to take place or were impossible.

The concept of whakama was again discussed and one participant explained how she went to the toilet or somewhere else private to use her inhaler as she did not wish to be identified as an asthmatic. Rongoa Maori were used occasionally by some asthmatics and others mentioned that when they were feeling good they 'wouldn't take their medication until symptoms appeared again'. It was also noted that at school many Maori asthmatics borrowed inhalers. All participants felt that there needed to be more referral of asthma patients to specialists.

Mt Eden Asthma Society rooms, Auckland – 11 October 1990

Approximately 60 people attended, a high proportion of these being young people of school age.

Many of the concerns that we had previously heard on our visits were again raised, particularly with respect to information about asthma, the lack of management plans, the difficulty with accessing health care and the poor attention given by some general practitioners to their asthmatic patients.

Current evidence has suggested that the Maori and non-Maori rates for asthma are about the same but these findings were vigorously challenged. It was felt that there was a need for more research into Maori asthma, not only its prevalence but also its sociology. There seemed to be little understanding of the impact of certain lifestyles on asthma. Smoking was an obvious adverse factor but sexual and physical abuse were also mentioned as important factors.

‘What is frightening about many Maori people is that their expectation of being normal is much less than it should be.’ Many Maori accept having asthma, ear problems, chest problems etc, as being normal for a Maori. The need for better information and more appropriate ways of developing and delivering that information should be considered. For instance, Maori people could well be used in an education role – *kanohi ki te kanohi*. Asthmatics would make good educators, an issue which has been raised at other hui.

Important korero came from the rangatahi present. They stressed that they had little understanding of asthma and wanted to know a lot more. Any information they gained about asthma was from their peers at school. The hui discussed poor communication between doctor and patient and gave the example of one doctor who used an egg-timer to control the length of his consultation. It was also felt that some Pakeha assumed it was their place to dispense education and health services when Maori people may have an important role to play here. The hui felt that there would be some merit in asthma programmes being marae-based or that ‘drop-in’ centres be established which could offer more detailed advice about asthma or even arrange referral to a specialist.

Te Paea Marae, Mangere – 11 October 1990

Approximately 15 people attended. The concerns expressed were similar to those of other hui. The particular aspects which were discussed at this hui concerned the whakama some patients felt with their asthma, the need for more marae-based clinics to deal with

asthma, and the view that agricultural sprays and smoking sparked off asthma. There was also some discussion about the role of diet in asthma. It was stressed that there needed to be an holistic approach to asthma management and that school teachers needed to be better educated about asthma. There was some concern about the availability of nebulisers for patients in distress with asthma.

Travelodge Hotel, Mangere – 11. October 1990

We hosted a small delegation of Maori Women's Welfare League members from Waiuku and a member of the Auckland St John Ambulance. The particular concern of the group concerned the close proximity of the Glenbrook Steel Mill to local marae. There was a feeling that asthma incidence had increased, and there had been several deaths due to asthma. We were asked to find out about any asthma research in the area and in particular the role of discharges from the steel mill in causing or aggravating asthma. A general discussion about the role of the St John Ambulance also took place.

Mangatangi Marae, Mangatangi – 12 October 1990

The review team was invited to attend the Poukai celebrations with the Tainui people at Mangatangi. This is an annual celebration where the Tainui people strengthen their support for each other and discuss important issues of the day and this included our review of asthma. Approximately 200 people attended and again the major issues that had been raised at previous hui were highlighted. The costs of going to the doctor were high and in many instances the health services were regarded as inaccessible. Some discussion about rongoa Maori took place and their proper use in conjunction with appropriate karakia stressed. Finally, it was felt that information about asthma was often not appropriate for Maori people and that smoking needed to be more actively discouraged.

Te Rerenga Marae, Whangarei – 12 October 1990

Approximately 25 people attended, several being non-Maori and health professionals. Again there were concerns relating to access to health care and the costs of medical treatment, and the need for more appropriate information about asthma for Maori people. Two paedia-

tricians were in attendance; they were unsure as to what proportion of their patients were asthmatic. There was the feeling that specialist referrals should be more accessible and it was suggested that public health nurses should be able to refer patients to specialists. It was also mentioned that the St John Ambulance was providing some training and education about asthma to local people.

Waimononi Marae, Waimononi – 13 October 1990

Twelve people attended this hui and many questions were asked about asthma and its management. The main concerns that were highlighted related to information about asthma, resources for asthma management, and the need for an asthma crisis plan. It was also felt that educational material should be culturally more appropriate. We were told how, at Te Hapua, whanau had combined with the Fire Brigade and others to provide a system of asthma emergency care in that very isolated area. Difficulties were mentioned in getting treatment at Kaitaia Hospital and sometimes it was not even easy to find a general practitioner. Finally, it was felt that individuals needed to take more responsibility for their asthma management and perhaps develop the idea of whanau support/emergency care more widely.

Airport Lodge, Wellington – 7 November 1990

Members from the NZ Asthma Foundation, health professionals and practitioners working in the field of complementary health attended this meeting.

An outline of the Asthma Foundation's activities was presented and in particular how Asthma Societies around the country coordinated their activities with the Foundation. The Foundation was keen to improve asthma services and research in the Maori community, acknowledging that cultural differences would require different approaches. Questions about the appropriateness of information and its communication were raised and it was also stated that the management of asthma was not wholly the responsibility of the country's general practitioners. With respect to asthma research, studies currently being carried out at Wairoa College were discussed by Dr Julian Crane.

Maraeroa Marae, Porirua – 8 November 1990

Approximately 40-50 people attended this hui – members of the community, health workers, asthmatics and those who had whanau who suffered with asthma.

The same major issues as outlined at previous hui were discussed, including problems with access to health care, the need for a simple management plan and the need for better information about asthma. It was recognised that the key person in the management of asthma was the general practitioner and there was a feeling that a good service was provided by the general practitioners in the area. There was a strong plea for more information about asthma and asthma drugs, not only for asthmatics themselves but also for members of the families of asthmatics.

The problems associated with whakama were again raised and this prevented some Maori asthmatics from seeking more help for their asthma. Generally it was thought that health professionals were not good at providing information about asthma and that their knowledge of asthma was variable. The high costs associated with visits to the doctor, particularly at weekends, were mentioned and also the high costs to chronic sufferers. A general discussion on gauging the severity of asthma took place and this highlighted the need for a simple action plan to be developed. It was also felt that school teachers needed to know a lot more about asthma and that asthma education might even be introduced into the school curriculum. Some criticism of the use of medical jargon about asthma was made. The idea of forming an asthma support group was also raised and there were many questions to the review team about all aspects of asthma management and its causes.

Cannons Creek School, Porirua – 8 November 1990

About six parents attended this small hui. It was felt that there would be some merit in an asthma information kit being developed and there was also the feeling that staff needed further training about asthma. It was also mentioned that there was very high absenteeism in asthmatic children particularly on rainy days.

Waiwhetu Marae, Lower Hutt – 8 November 1990

Approximately 20 people attended this hui, many being Maori and asthmatic. Again, the issues raised at this hui were little different from those discussed at previous hui. Many questions about asthma were asked. Smoking was mentioned as a particular problem with asthma and it was also noted that many patients did not bother to take any medication when feeling well. There was also some criticism that doctors lacked cultural understanding about their Maori patients and this hindered good communication. It was felt that Maori people would make good asthma educators. There was some discussion about the place of rongoa Maori in the treatment of asthma and also questions were asked about the role of the diet in asthma. The costs of attending doctors and the costs of medication were highlighted as significant barriers to health care.

Newtown Union Health Service, Wellington – 9 November 1990

Approximately 15–20 people attended this hui which gave us a good insight into the role that a low cost centre might play in asthma management. People attending the union health clinic were generally from poorer families who might be expected to have greater problems when accessing health care. Charges for consultations were kept low but in spite of this there were probably fewer Maori people attending than expected. Whakama was mentioned again as an important barrier to attendance at the centre with many parents feeling embarrassed at the poor health of their children. These same people tended to blame themselves for any family ill health. Particular problems were highlighted with people who had no phones, lack of transport and little money. Many families too were on the move. The need for better information and support services relating to asthma was highlighted and it was noted the clinic employed a Maori liaison officer who dealt with some of these issues. In general those Maori patients attending the union health service were very complimentary about the care they received.

Manukorihi Marae, Waitara – 19 November 1990

Approximately 30 people attended this hui, including some health professionals and a paediatrician. We were asked many questions relating to asthma and again many of the problems we had heard at other hui relating to asthma were raised. The principal concerns were the accessibility of appropriate information and educational material about asthma and the feeling that Maori people themselves would be good educators. Access to health care was highlighted as a major problem, particularly the costs of doctors' visits and medications. The concept of whakama was discussed at length and particularly its relationship to the confiscation of lands in Taranaki and colonisation of the area. There were also some questions relating to the possible role that the Motunui petrochemical works might play in precipitating asthma in the area. Problems in the access of asthma patients to accident and emergency services were raised. The need for an asthma management plan was stressed.

Waitahanui Marae, Taupo – 21 November 1990

Approximately 20 people attended this hui including one of the local general practitioners. Major concerns were expressed at the cost of visits to the doctor and the cost of asthma medications. It was also mentioned that asthma management was considerably aggravated by smoking tobacco and marijuana, and drinking alcohol. The hui felt that there was a need for more information and educational materials about asthma and a need for Maori people as educators. Rongoa Maori had an important role to play in the management of asthma in some people and kumara hou, kawakawa, snails, karamu, tutu were all cited as being useful. An holistic approach to asthma management was highlighted, the wairua being important in this respect. Whakama was again discussed as a barrier to health care. Finally it was suggested that, in view of the serious financial problems in meeting doctors' charges, no charges should be made for children under the age of five years for doctors' visits or medications.

Recommendations

A

A major improvement in Maori asthma will only occur through more effective involvement of Maori people in the planning and delivery of asthma care.

- 1 The Asthma Foundation/Department of Health/Ministry of Maori Affairs and Regional Health Authorities should prioritise resources for Maori asthma, particularly for education/information and research activity.
- 2 The Asthma Foundation should form a Maori Asthma Committee including a kaumatua with representation from both the Foundation and the Maori community. The committee should have a leadership role on all aspects of asthma in the Maori community.
- 3 Through its Maori Asthma Committee, the Asthma Foundation should explore ways of increasing substantially its Maori membership and informing Maori people of its existence, aims and objectives.
- 4 The Asthma Foundation should set up a community development putea to fund Maori asthma projects. Such an involvement by the Asthma Foundation in the Maori community would help enhance the Foundation's credibility within that community. Applications for funds would be reviewed by the Maori Asthma Committee.
- 5 There should be significant Maori involvement and participation in all asthma policy and funding initiatives affecting Maori people, both at a community and regional level.

B

Improved access to health care is vital if Maori asthma statistics are to improve.

- 1 Free medical care should be available for asthmatics who are beneficiaries or on low incomes.
- 2 Asthma medications should be free or attract a small part-charge only. For instance, preventer medications might be marked free while reliever medications have a small part-charge.
- 3 Low cost health clinics should continue to be established. For instance, union health clinics were seen by many Maori as helping to facilitate their access to health care.
- 4 More ready referral of Maori patients with asthma to asthma specialists/clinics should be encouraged.
- 5 Regular visits by asthma specialists to geographically isolated areas, eg, Chatham Islands, Mahia Peninsula, Te Hapua, should be organised.
- 6 Marae-based (or similar) asthma clinics with significant Maori management should be established. These should be adequately funded, and employing 'culturally safe' staff. The aim of such clinics would be to overcome cultural barriers in addition to those of location and money.
- 7 Services for asthma should be available at locations and times that fit in with public transport. In those instances where convenient public transport is not available, transport might be provided by the regional or local health authority or local community transport rosters. Mobile clinics should be used in remote areas.
- 8 Awhina huango should be trained. Such persons will have a central role in providing the means for dealing with asthma emergencies in isolated areas. It is possible that such isolation may even occur within large metropolitan areas.
- 9 Accident and emergency services should be prepared and available at all times to receive patients with acute asthma.

- 10 Extra funding for asthma services and medications should be a priority to counteract the extreme isolation of the Chatham Islands.

C

Education about all aspects of asthma and its management is vital for optimal treatment success. Maori people have expressed a strong desire to be involved in all aspects of the education process.

- 1 A National Maori Asthma Education Coordinator (Kaiwhaka-haere Huango) should be appointed through the Asthma Foundation with funding from the Department of Health and the Ministry of Maori Development. This person would have many responsibilities but the most important of these would be to run a series of training workshops to train Maori asthma resource people. The national coordinator would be responsible for emphasising self-management, whanau support and the use of an action plan. This person would also encourage the formation of Maori asthma support groups and ensure that Maori tikanga is followed at all times. The coordinator would also be responsible for developing ongoing plans for education/information development and promotion and should help identify and support awhina huango.
- 2 A Maori asthma resource person should be appointed in each of the 10–15 Maori districts (these districts could be defined along the lines of the old area health boards, or a similar division). These people should be adequately funded and trained and be acceptable to the Maori community. They would have an important role in the training of awhina huango whose role would be to provide asthma education to individual asthmatics and their whanau.
- 3 A workforce of voluntary awhina huango should be trained. Such persons may be asthmatics themselves with first-hand experience of the condition. They would have an important role in educating other members of whanau, hapu or iwi about all aspects of asthma, including its management.

- 4 Continuing education programmes on asthma should be encouraged for medical practitioners and ways of ensuring their ongoing competency in dealing with the management of asthma patients should be explored. The College of General Practitioners might provide a leadership role in this area.
- 5 Funding from Vote Health should be provided for asthma education in Te Kohanga Reo.

D

Information and education material about asthma needs to be available and appropriate if management is to be optimised. Oral and visual materials are favoured by many Maori people.

- 1 Asthma hui should be encouraged and supported by the Maori Asthma Committee of the Asthma Foundation, Department of Health, Ministry of Maori Development and Regional Health Authorities.
- 2 Plans to use Maori radio to disseminate information about asthma including the location and access to services should be developed.
- 3 Appropriate video material and asthma fact sheets should be developed. Particular emphasis should be given to the development of these materials by Maori people using communication techniques which are more likely to be successful at informing Maori.
- 4 Asthma educators and other health professionals involved in asthma health service delivery and asthma education should be encouraged to communicate in straight-forward language without jargon.

E

Pakeha health workers need to be aware of and sensitive to cultural factors which adversely affect Maori asthma management.

- 1 A programme of 'cultural safety' should be included in the training of health workers.

- 2 Pakeha health workers should be educated in cultural matters by encouraging their involvement in Maori health initiatives.

F

Research is important if the causes of asthma are to be found and existing/new programmes are to be properly evaluated. Maori people have several areas they wish to be specifically researched.

- 1 The Asthma Foundation/Health Research Council fund, as a priority, should undertake research into asthma among Maori people. Particular areas which should be considered include:
 - prevalence/incidence of asthma in Maori people, including regional differences;
 - possible causes of asthma in New Zealand, such as pine pollen, agricultural sprays and industrial emissions (for example, those from the steelworks at Waiuku);
 - the implementation of an action plan for adults in the Maori community.
- 2 The systems of classification of ethnicity should be modified to include self-identification where possible. Standardisation of classification for research and data-gathering purposes should be undertaken and Maori people should be fully involved in these processes and have the right to veto decisions and re-enter discussion.
- 3 A simple management plan for asthma in Maori children should be developed, implemented and evaluated.

G

Tobacco smoke is bad for asthma. The high prevalence of smoking among Maori must be reduced.

- 1 The establishment of non-smoking initiatives and smokefree areas should be encouraged and supported.
- 2 The anti-smoking legislation should be supported.

H

An action plan for the management of asthma should be made available to the Maori community and be user-friendly.

- 1 Emphasis should be given to the use of the adult asthma action plan presented in Chapter 3 and recently tested in the Wairarapa. Such plans should be adopted and implemented by Maori people in partnership with other health workers. Action plans should be simple to understand not only by the asthmatic but also by his or her whanau and friends.
- 2 The current role of preventer and reliever medicines should be emphasised with particular focus on the use of preventer medications.
- 3 Rongoa Maori have a complementary role in the treatment of asthma and may be of benefit if used in conjunction with conventional therapy.
- 4 The use of peak flow meters in conjunction with an action plan should be actively encouraged. These should be made more freely available through Asthma Societies.
- 5 A 24-hour asthma line for asthma emergencies should be established and operated by Maori people.
- 6 General practitioners should be encouraged to refer patients to asthma specialists for second opinions.
- 7 The Department of Health in conjunction with the Asthma Foundation should be encouraged to provide additional independent, up-to-date information about asthma management to promote the highest standards of asthma care. Information relating to asthma management is often supplied by drug companies promoting a particular product.

The key person in the long-term management of asthma is the informed patient.

Glossary

iwi	tribe
hapu	sub-tribe
whanau	family
runanga	confederation of tribes
te reo	language
nga putake	foundations of health
whanaungatanga	family health
te ao Maori	the Maori world
kuia and kaumatua	female and male elders



APPENDIX 1

Written submissions

Thirty-three written submissions were received, the majority after the closing date. Most were from asthma sufferers and six were from medical practitioners. Many important areas were highlighted and these complemented the large number of oral submissions from our review hui. The major areas highlighted were:

- financial barriers to health care including costs of general practitioner visits, medications and transport;
- the need for more appropriate information and educational materials about asthma including asthma drugs;
- asthma education for Maori by Maori – consideration of the role for te kohango reo;
- the need for a clear and simple asthma management plan;
- more education for health professionals on Maori cultural perspectives;
- poor relationships between Maori clients and some general practitioners hindering adequate management;
- more research into asthma and its causes;
- greater availability of specialist services for Maori asthmatics and more asthma clinics, either marae or whanau-based, especially in geographically isolated areas;
- the detrimental effects of tobacco and marijuana smoking on asthma;
- the complementary use of alternative therapies or rongoa Maori in the management of asthma;
- the development of asthma support groups and more active role for Maori in asthma societies;
- specialist and mobile services for asthmatics in geographically isolated areas;

- under-diagnosis of asthma;
- role of emergency services in acute asthma management, eg St John Ambulance;
- relationship of weather patterns in asthma.

These are the major points raised in submissions from the following: Dr Patricia Holborrow, Wellington; Beverly Allison, Upper Hutt; Martha Moon, Kaikohe; Brian Booth, Palmerston North; Tai Tokerau, Te Kohanga Reo; Lorna Hughes, Tairāwhiti Area Health Board; Dr Bobby Tsang, Northland Area Health Board; Doug Miller, Otago Area Health Board; Rangi Eria, Napier; Maria Bryson, Otago Polytechnic; Merania Karaunia and Michael Buist, Wellington; Daphne Olsen, Paraparaumu; Maria Clark, Waiuku; Mary Reed, Wairoa; Aroha Mead, Wellington; Rene DeJongh, Manawatu-Wanganui Area Health Board; John Hannifin, Palmerston North Drugs Advisory Committee; Anne Cressey, NZ Plunket Society; Dr J Garrett, Greenlane/National Women's Hospitals; Yvonne Amery, Manurewa; Dr Leo Buchanan, Community Paediatrician, Waikato Area Health Board; Reese Forbes, Opotiki; Te Aomihi George and Erica McHardy, Rotorua; Deborah Ryburn, South Auckland Asthma Centre; Dr Phyllis Taylor, West Auckland District Health Services; Richard Beasley, Wellington School of Medicine; Jenny Grainger, Mahora Tamahori, Florence Skipper, Iwi Parker, Maud Gillespie, Pauline Boyles, Peter Browne – people of West Coast District, Wellington Area Health Board; Asthma Foundation; Margaret Vodonavich, Auckland Area Health Board; Linda Smith, University of Auckland; Dr C Moyes, Bay of Plenty Area Health Board; H Dansey, The Order of St John, Auckland; D Craig, Maori Health Service Advisory Group, Otago Area Health Board; Paul Bruce, NZ Meteorological Services, Wellington; Dr David Barry, Paediatrician, Hastings.

APPENDIX 2

General outlines toward culturally safe practice

- 1 Be aware that each turoro does not stand alone but is part of a whanau, all of whom have rights in relation to their whanaunga. Consultation, negotiation and choice extends to whanau. Situations will, of course, vary but it is safe practice to include whanau rights until demonstrated otherwise.
- 2 Avoid imposition of other cultural values by facilitating choices and by negotiation with each turoro being prepared to accept the decision of turoro unless it endangers life or the public good. Further negotiation is then required.
- 3 Make access to Maori community resources possible from first contact. If any turoro wishes for contact with the Maori community, do not obstruct it, but work with it.
- 4 Be aware of the constant dimension of wairua, this can often directly affect the recovery of turoro Maori.
- 5 Be aware that members of minority groups observe all the non-verbal behaviour of members of the power groups. Decisions about how to respond are frequently made on the initial 'readings' rather than on what a nurse may eventually say. For example, bustling behaviour may be interpreted as impatience and a wish to move on. Turoro may choose to remain silent or give assent rather than discuss issues of concern. This kind of observation is a survival technique.
- 6 Consider the dignity and humanity of the turoro Maori as with all turoro (approach, attitude and negotiated advocacy). Do not consider that the nurse is necessarily the appropriate advocate for Maori people.

- 7 Do not make decisions on cultural safety alone. If in doubt, ask. People are grateful to see a genuine effort. Everything is to be gained by consultation and mutual agreement.
- 8 If a culturally unsafe situation is suspected or observed, inform turoro or the whanau that a Komiti Whakaruruhau can make an informed decision resulting in modification of behaviour or discipline. A process of complaint and adjudication is available to turoro with the rights of nurse, turoro and whanau held equally.
- 9 There is a fundamental difference in attitude between western trained nurses and nurses from the tangata whenua. The idea of 'mokai' in the Maori reality indicates that a skilled person from the people has an obligation to serve the community by the use of those specialised skills. The obligation of service is deeply imbedded in many Maori who recognise that survival of western education systems implies an obligation to those who have not been so fortunate. The price can often be very high for the survivor in terms of individualisation and isolation.

The difference lies in the individual and collective concepts of the two cultures.

APPENDIX 3

Ottawa Charter for Health Promotion

The first International Conference on Health Promotion, meeting in Ottawa this 21st day of November 1986, hereby presents this charter for action to achieve Health For All by the year 2000 and beyond.

This conference was primarily a response to growing expectations for a new public health movement around the world. Discussions focused on the needs in industrialised countries, but took into account similar concerns in all other regions. It built on the progress made through the Declaration of Primary Health Care at Alma Ata, the World Health Organisation's Targets for Health For All document, and the recent debate at the World Health Assembly on intersectoral action for health.

Health promotion

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being.

Prerequisites for health

The fundamental conditions and resources for health are peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity. Improvement in health requires a secure foundation in these basic prerequisites.

Advocate

Good health is a major resource for social, economic and personal development and an important dimension of quality of life. Political, economic, social, cultural, environmental, behavioural and biological factors can all favour health or be harmful to it. Health promotion action aims at making these conditions favourable through advocacy for health.

Enable

Health promotion focuses on achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men.

Mediate

The prerequisite and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organisations, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities. Professional and social groups and health personnel have a major responsibility to mediate between different interests in society for the pursuit of health.

Health promotion strategies and programmes should be adapted to the local needs and possibilities of individual countries and regions to take into account differing social, cultural and economic systems.

Health promotion action means: build healthy public policy

Health promotion goes beyond health care. It puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health.

Health promotion policy combines diverse but complementary approaches including legislation, fiscal measures, taxation and organisational change. It is coordinated action that leads to health, income and social policies that foster greater equity. Joint action contributes to ensuring safer and healthier goods and services, healthier public services, and cleaner, more enjoyable environments.

Health promotion policy requires the identification of obstacles to the adoption of healthy public policies in non-health sectors, and ways of removing them. The aim must be to make the healthier choice the easier choice for policy makers as well.

Create supportive environments

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitute the basis for a socio-ecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance – to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasised as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organises work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment – particularly in areas of technology, work, energy production and urbanisation – is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environment and the conservation of natural resources must be addressed in any health promotion strategy.

Strengthen community action

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.

Develop personal skills

Health promotion supports personal and social development through providing information, education for health and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.

Enabling people to learn throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and within the institutions themselves.

Re-orient health services

The responsibility for health promotion in health services is shared among individuals, community groups, health professionals, health service institutions and governments. They must work together towards a health care system which contributes to the pursuit of health.

The role of the health sector must move increasingly in the health promotion direction, beyond its responsibility for providing clinical and curative services. Health services need to embrace an expanded mandate which is sensitive and respects cultural needs. This mandate should support the needs of individuals and communities for a

healthier life, and open channels between the health sector and broader social, political, economic and physical environment components.

Re-orienting health services also requires stronger attention to health research as well as changes in professional education and training. This must lead to a change of attitude and organisation of health services, which refocuses on the total needs of the individual as a whole person.

Moving into the future

Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.

Caring, holism and ecology are essential issues in developing strategies for health promotion. Therefore, those involved should take as a guiding principle that, in each phase of planning, implementation and evaluation of health promotion activities, women and men should become equal partners.

Commitment to health promotion

The participants in this conference pledge:

- to move into the arena of healthy public policy, and to advocate a clear political commitment to health and equity in all sectors;
- to counteract the pressures towards harmful products, resource depletion, unhealthy living conditions and environments, and bad nutrition; and to focus attention on public health issues such as pollution, occupational hazards, housing and settlements;
- to respond to the health gap within and between societies, and to tackle the inequities in health produced by the rules and practices of these societies;
- to acknowledge people as the main health resource; to support and enable them to keep themselves, their families and friends healthy through financial and other means, and to accept the community as the essential voice in matters of its health, living conditions and well-being;

- to re-orient health services and their resources towards the promotion of health; and to share power with other sectors, other disciplines and most importantly with people themselves;
- to recognise health and its maintenance as a major social investment and challenge; and to address the overall ecological issue of our ways of living.

The conference urges all concerned to join them in their commitment to a strong public health alliance.

Call for international action

The conference calls on the World Health Organisation and other international organisations to advocate the promotion of health in all appropriate forums and to support countries in setting up strategies and programmes for health promotion.

The conference is firmly convinced that if people in all walks of life, non-governmental and voluntary organisations, governments, the World Health Organisation and all other bodies concerned join forces in introducing strategies for health promotion, in line with the moral and social values that form the basis of this charter, health for all by the year 2000 will become a reality.

APPENDIX 4

Declaration of Alma-ata

- 1 The conference strongly affirms that health, which is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide goal whose realisation requires the action of many other social and economic sectors in addition to the health sector.
- 2 The existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.
- 3 Economic and social development, based on a New International Economic Order, is of basic importance to the fullest attainment of health for all and to the reduction of the gap between the health status of the developing and the developed countries. The promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life and world peace.
- 4 The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.
- 5 Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organisations and the whole world community in the coming decades should be the attainment of all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health

care is the key to attaining this target as part of development in the spirit of social justice.

- 6 Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.
- 7 Primary health care:
 - (1) reflects and evolves from the economic conditions and socio-cultural and political characteristics of the country and its communities and is based on the application of the relevant results of the social, bio-medical and health research and public health experiences;
 - (2) addresses the main health problems in the community, providing promotional, preventive, curative and rehabilitative services accordingly;
 - (3) includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition, and adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunisation against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs;
 - (4) involves, in addition to the health sector, all related sectors and aspects of national and community development, in particular agriculture, animal husbandry, food, industry, education, housing, public works, communications and other sec-

- tors; and demands the co-ordinated efforts of all those sectors;
- (5) requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
 - (6) should be sustained by integrated, functional and mutually-supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need;
 - (7) relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.
- 8 All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilise the country's resources and to use available external resources rationally.
 - 9 All countries should cooperate in a spirit of partnership and service to ensure primary health care for all people since the attainment of health by people in any one country directly concerns and benefits every other country. In this context the joint WHO/UNICEF report on primary health care constitutes a solid basis for the further development and operation of primary health care throughout the world.
 - 10 An acceptable level of health for all the people of the world by the year 2000 can be attained through a fuller and better use of the world's resources, a considerably part of which is now spent on armaments and military conflicts. A genuine policy of independence, peace, defence and disarmament could and should release additional resources that could well be devoted to peaceful aims

and in particular to the acceleration of social and economic development of which primary health care, as an essential part, should be allotted its proper share.

The International Conference on Primary Health Care calls for urgent and effective national and international action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical cooperation and in keeping with a New International Economic Order. It urges governments, WHO and UNICEF, and other international organisations, as well as multilateral and bilateral agencies, non-governmental organisations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The conference calls on all the aforementioned to collaborate in introducing, developing and maintaining primary health care in accordance with the spirit and content of this Declaration.

APPENDIX 5

Costs of recommendations

- 1 Information and education materials
 - Includes cost of production and distribution of an asthma video, printed materials, such as pamphlets, stickers, T-shirts etc, and TV advertisements and radio programmes

Estimated cost \$250,000

- 2 Seeding grants for asthma support groups
 - The cost of one resource kit containing a video and information about asthma
 - Costs relating to update of resource information, travel, koha, miscellaneous fees and accommodation (estimated cost per support group is \$2500)

Total estimated cost for 20 support groups throughout New Zealand \$50,000

- 3 Health professional education (includes general practitioners/ other health providers)
 - Costs relating to half/one-day seminar, resource kit, fee for facilitator of seminar (estimated* cost per seminar \$1000)

Estimated cost for 20 seminars \$20,000
(*Costs will depend on number attending seminars)

- 4 National hui on asthma for Maori health providers (100 people for two days)
 - Costs for marae at \$50 per head per day \$10,000
 - Travel (presenters, rental vehicles) \$2,000
 - Report/resource kit \$5,000
 - Incidentals and administration \$2,000

Estimated cost of hui \$19,000

5 Government assistance for asthma programme

- Costs to have a Maori unit/executive officer/Maori committee within the Asthma Foundation

Maori unit

– personnel/coordinator	\$45,000–\$50,000
– executive support	\$30,000–\$35,000
Subtotal	<u>\$75,000–\$85,000</u>

Operational

– travel/accommodation (promotion, distribution of information within whānau, hapu, iwi, health providers, koha included)	\$15,000
– training (seminar/course fees)	\$2,000
– administration (reports/newsletter) costs may be shared with the Foundation	\$10,000
– projects and research	\$30,000
Subtotal	<u>\$50,000–\$57,000</u>

Overall estimated cost \$132,000–\$142,000

- Te Kohanga Reo – part salary for health coordinators within 12 Te Kohanga Reo districts
 - ongoing training, travel/accommodation/fees/resource kit × 2 per year \$1,000
 - \$10 × 15 hours (estimated average) × 40 weeks = \$6,000
- Estimated total cost \$7,000

- Maori asthma resource persons with area health board/Asthma Society
 - community worker \$15 per hour × 40 hours × 52 weeks = \$31,200

Estimated cost for the equivalent of 15 area health board districts \$468,000

- Basic training course for awhina huango – courses could be in partnership with Asthma Foundation/Asthma Society/area health board
 - two-day course (12–15 people)
 - cost of venue – \$300–\$500
 - resource kits – \$30 per person
 - presenter’s koha/fee – negotiate
 - travel \$5,000

Estimated cost of each two-day course	<u>\$6,000</u>
Estimated cost for 15 courses	<u>\$90,000</u>
Overall total estimated cost for asthma recommendations	<u>\$1,046,000</u>

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