He Māramatanga Huangō: Asthma Health Literacy for Māori Children in New Zealand

Report to the Ministry of Health
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This report was prepared by the University of Otago for the Ministry of Health and the Asthma Foundation of New Zealand.

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Foreword for He Māramatanga Huangō (Understanding Asthma)

In March 2014 I was pleased to host the Asthma Foundation 50th Birthday and Achievers Awards Dinner at Government House. There I met many brave people who live with debilitating respiratory conditions. One of those people was Esther-Jordan Muriwai, who had severe bronchiectasis. Despite her illness, Esther-Jordan set herself the task of setting up the Bronchiectasis Foundation and convinced me to be its patron. Sadly, she passed away before the Foundation was launched earlier this year.

As patron of the Asthma Foundation, I appreciate its role in advancing and promoting research into respiratory diseases, including bronchiectasis. We need to learn as much as possible if there is to be any further progress in lowering our high rate of hospital admissions and deaths due to these respiratory diseases.

I therefore welcome the decision of the Asthma Foundation and the Ministry of Health to commission research from the University of Otago and to produce this report, He Māramatanga Huangō (Understanding Asthma). While there have been pleasing improvements in some areas, I note the continuing concerns about inequality of health outcomes across different communities in New Zealand. It is to be hoped that the recommendations in this report, including measures to more comprehensively tackle health illiteracy, will provide a new way forward.

I congratulate everyone involved in bringing this research to a wider audience. I am sure it will be welcomed by patients, health-care workers, educators, families and policy-makers as they work together to improve the health outcomes for New Zealanders living with respiratory diseases.

Lt Gen The Rt Hon Sir Jerry Mateparae, GNZM QSO
Governor-General of New Zealand
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EXECUTIVE SUMMARY

He Māramatanga Huangō: Asthma Health Literacy for Māori Children in New Zealand
EXECUTIVE SUMMARY

“Tihei mauri ora (behold the breath of life)!”

This report presents findings of the He Māramatanga Huangō (Understanding Asthma) research project commissioned from the University of Otago by the Ministry of Health and the Asthma Foundation of New Zealand.

Background

Asthma symptomatically affects over 26% of New Zealand children, a rate that is amongst the highest in the world. The burden of asthma is considerable. Forty-two percent of asthmatic children are ‘uncontrolled’, 12% miss school each month, and 14% attend an emergency department or are admitted to hospital with asthma each year. New Zealand has the highest death rate from asthma amongst high-income countries. The medical and economic costs of asthma in New Zealand are estimated to be $800 million per year.

Inequalities in asthma outcomes for Māori children are striking: Māori have significantly higher rates of hospitalisation; suffer higher severity of asthma symptoms; are less likely to have a peak flow meter or asthma action plan; and fewer are prescribed preventive treatments, resulting in poorer overall control. While the prevalence of asthma has decreased for New Zealand European children over the past few decades, this reduction has not occurred for Māori. Clear recommendations for strategies to reduce these disparities have been available since a review of Māori asthma, ‘He Mate Huangō’, was commissioned in 1991, yet many of these recommendations remain unimplemented. Addressing the burden of childhood asthma for Māori is a critical issue warranting urgent action.

Evidence suggests that low health literacy is associated with poorer self-efficacy and reduced use of asthma medication, and poorer health outcomes. Health literacy, which has been defined as “the extent to which individuals have the ability to obtain and understand basic health information and services needed to make appropriate health decisions”, is gaining increasing recognition as a significant potential contributor to poor health outcomes. Population surveys indicate that a large proportion of the New Zealand population has poor health literacy, with reported levels worse among Māori – adversely affecting health outcomes.

However, health literacy is more than an individual skill set: it is a complex interaction between the demands of the health system and the skills of those engaged with that system. It is now recognised that health literacy is a dynamic systems issue, reflecting the complexity of health information being presented and the health care system being navigated. Complex medical conditions, wide-ranging treatment options and service provision, as well as an array of communication channels, further influence health literacy demands for patients and families. Consequently, changes are needed at the health professional, health organisation and health system levels if the issue of health literacy is to be addressed.
**Purpose**
The project was intended to inform health policy, service delivery and resource development by:

1. examining the health literacy demands on both whānau (family) and health providers regarding asthma management
2. investigating and identifying health literacy barriers and facilitators
3. identifying gaps in and issues with asthma health literacy skills and knowledge
4. making recommendations to improve health literacy, in order to improve asthma outcomes for Māori children.

**Methods**
The study utilised a Kaupapa Māori Research (KMR) methodology to guide and inform our research processes using the Whānau Tuatahi Framework previously developed by our team. The research was shaped by the concepts of: whakawhirinaki (trust), ngāwari (flexibility), whakawhanaungatanga (building relationships), whakamana (empowerment), utu (reciprocity) and hurihuringa (reflexivity).

A mixed methods approach was used, combining qualitative and quantitative methods to explore the ideals and expectations for asthma health literacy, along with the practical experiences and capacities for asthma management from the perspectives of both health professionals and whānau.

The following methods were employed to collect data within this project.

1. A panel of 14 asthma experts was convened to develop a list of essential asthma skills and knowledge required by parents managing their child’s asthma.
2. A national online survey was completed by 800 health professionals with a role in asthma management (nurses, GPs and clinicians, pharmacists and asthma educators).
3. In-depth, semi-structured interviews were held with a range of health professionals and other provider staff directly involved in managing Māori children with asthma. Participants from five health providers in the greater Wellington and Auckland regions came from a range of disciplines: primary care nurses, GPs, pharmacists, practice managers and health-care workers.
4. Seventeen in-depth semi-structured interviews and three focus groups were held with Māori whānau who have a child with asthma. Eligible children were of New Zealand Māori ethnicity, aged 4–18 years and living in the Greater Wellington or Auckland Region. A variety of self-assessment tools (e.g. a card-sort knowledge self-assessment tool) were used in conjunction with the interviews and focus groups.
5. Finally, written resources were reviewed according to criteria derived from the Ministry of Health guidelines and those developed by the Workbase Education Trust.

Core strengths of this research project included the kaupapa Māori methodological approach and the Māori community partnerships, which yielded significant community and health sector buy-in, while also protecting the mana and integrity of the research participants.
Findings

From health professionals and providers we identified the following.

• There are a considerable number of generic and disease-specific knowledge demands implicit in the optimal management of childhood asthma. These demands are complicated, and involve an extensive terminology, complicated risk factors, limited/subjective measures of control, difficulties achieving outcomes, and balancing patients’ risks and expectations.

• Health professionals recognise the importance of health literacy in the effective management of childhood asthma; however, none of the provider staff interviewed reported having received any training in education or health literacy approaches.

• GPs acknowledged that asthma education for their patients is largely focused on medication compliance and relies most heavily on face-to-face verbal communication strategies, with very few regularly using pictures, audio-visual aids, models or internet technology.

• Many provider staff admitted to having difficulties assessing the level of understanding of their Māori patients or eliciting questions from them.

• Health professionals identified a high burden of barriers to effective asthma management within their patient’s families, including: misperceptions regarding medications, lack of knowledge regarding the nature and potential seriousness of asthma, along with housing conditions. Health professionals recognised significantly fewer barriers within the health-care system.

• Provider staff noted that the current model of primary health care provides limited capacity to address chronic asthma management (e.g. time constraints, acute presentations, lack of follow-up visits). However, health professionals did emphasise that for asthma education to be successful, it could not be considered a one-off, but a longitudinal process over time involving a consistent relationship between the health professional, the child and their family.

From whānau we identified the following.

• Self-reported confidence with asthma health literacy varied considerably amongst whānau, with fewer than half reporting a high level of confidence in understanding what asthma is.

• Fewer than half of whānau expressed confidence in understanding about asthma plans, with a third stating they knew little or nothing about them. Only two-thirds of whānau expressed confidence in knowing how to access urgent medical help.

• A significant discrepancy was noted, across all domains of self-assessed asthma knowledge, between tangible knowledge and abstract knowledge (i.e. low- versus high-order cognitive skill). For example, many whānau reported understanding how to complete tasks (e.g. use an inhaler or peak flow meter), but far fewer reported understanding why, or how they might help.

• Most whānau felt that they did not get told enough about their child’s asthma to manage it effectively, noting a lack of information on: the stages of disease, indicators of severity, the potential seriousness of the condition, common triggers, and the role of the various medications. Several whānau reported that they had never been provided with a formal asthma plan.

• Many whānau expressed difficulty with asking doctors to explain about asthma in a consultation visit due to perceived lack of time or not knowing how to articulate their questions.

• Several whānau reported that they had unresolved issues or on-going concerns that had not been addressed, particularly concerns regarding medication side-effects. Other parents expressed a sense of ‘not being listened to’ by their health professional or not being recognised for the insights they could offer into their child’s condition.

• Whānau expressed a desire for health professionals not to assume what they knew about asthma but to use a step-by-step approach when educating about asthma management.

• Establishing a trusted relationship with health professionals was an overwhelming priority for all whānau interviewed. There was a preference to have a regular GP, with concern expressed that they often see a different health professional at each visit and receive inconsistent advice.
**Whānau Ideals & Expectations**
- No jargon
- Emphasise key messages
- Provide consistency of advice
- On-going relationships with health professionals valued – generate trust
- Need to feel ‘listened to’
- Place importance on holistic health
- Step-wise approach to learning
- Information needs to be given in multiple ways, multiple times
- Resources designed for Māori needed
- Audio-visual resources preferred
- Support to confidently self-manage
- Prefer minimal dependence on medications
- Important to not feel ‘judged’

**Provider Ideals & Expectations**
- Supportive parents essential
- Parents need to be aware of asthma triggers and potential seriousness
- Medication adherence is important
- Comprehensive asthma services are needed
- Sufficient time must be available for on-going asthma education
- Best approaches to use for asthma education involve parent and child
- Important to be able to provide follow-up for patients
- Consistent information for parents
- Regular GP essential to developing on-going trusted relationship

**Whānau Experiences & Capacity**
- Doctors make assumptions about extent of parents’ knowledge
- Too much information given at once
- Inconsistent messages
- ‘You don’t know what you don’t know’
- Difficulty interpreting signs of asthma
- Unclear what to do and when
- Taught the ‘what’ not the ‘why’
- Confusion over medication types
- Fear of medication side-effects
- Lack of action plans
- Accessibility: services, costs, schools
- Relationships: not listened to / judged
- Normalisation of poor health
- Self-blame

**Provider Experiences & Capacity**
- Late presentations and poor treatment compliance commonplace
- Frustrated that unable to address underlying determinants of health
- Patients don’t take asthma seriously or parents don’t recognise asthma signs
- Hard to gauge a patient’s understanding, and Māori parents seldom ask questions
- Building rapport more difficult with Māori patients
- Limited time and capacity to provide on-going education or follow-up
- Lack of easily available and useful resources
- Limited access to in-service training opportunities
- Limited access to best-practice advice
This study demonstrated that the health literacy demands of managing a child with asthma are complex and multi-faceted. It was apparent that whānau were making significant efforts to effectively manage their child’s asthma with the knowledge and skills they have, though most were under-confident in their own abilities and recognised the need for more understandable asthma information. Whānau expressed widespread frustration at the lack of proactive holistic care and at the failure of the health system to respond to their needs. Similarly, there was widespread recognition amongst health professionals of the importance of health literacy to optimal asthma management. It was evident that most were making genuine efforts to recognise the needs of their patients and deliver information in understandable ways. However, it was also clear that they face a number of challenges in delivering quality asthma care – due predominantly to lack of adequate capacity, resources and specific health literacy training.

**Recommendations**

In determining our recommendations we have adopted a systems approach to health literacy to avoid the deficit notion whereby poor health literacy is considered the responsibility of the patient/whānau. All whānau have their own levels of knowledge, skill and internal resources to manage a chronic illness; however, it is our assertion that the health system must accommodate whānau equitably. We conclude that the predominant barriers to optimal health literacy for Māori children with asthma are structural, endemic to the acute care model of health-care delivery that currently predominates.

*We therefore advocate for a systematic health-literacy-based approach to asthma education for Māori children.*

We present recommendations under four emergent themes arising from the thematic analysis:

1. **Mātauranga (Knowledge):** Delivering Understandable Best Practice Asthma Advice for Māori Children
2. **Whakaakoako (Teaching Strategies):** Using Effective Strategies to Communicate About Asthma with Māori Children
3. **Whakawhanake (Workforce Development):** Building Relationships and Working Together to Support Māori Children with Asthma
4. **Te Anga (Model of Care):** Health Care Services That Meet the Health Needs of Māori.

Within each theme, we present an over-arching recommendation and recommended actions, according to a three-level hierarchy: Health Systems (macro level), Health Organisations (meso level), and Health Professionals (micro level).
1. Mātauranga (Knowledge)

Health System

The health system needs to recognise the burden of asthma facing New Zealand society, and Māori children in particular. It must take action to promote widespread public awareness of asthma, and ensure that up-to-date, New Zealand-specific, childhood asthma management guidelines are available to benchmark best practice and ensure consistency of advice.

- Promote enhanced public awareness of asthma, its potential seriousness and preventive measures.
- Work in partnership with the education sector to integrate fundamental asthma health knowledge into school curricula.
- Update New Zealand-specific best-practice management guidelines for paediatric asthma.
- Develop step-wise learning objectives and a curriculum for asthma management.
- Fund research that provides evidence for effective asthma interventions that activate and empower whānau to support children with asthma.

Health Organisations

Health organisations need to assume responsibility for the maintenance of best-practice standards within their organisation and for the provision of in-service training of their staff with respect to asthma management. Asthma is a chronic disease; therefore health organisations need to ensure their processes and information systems enable a longitudinal step-wise process of asthma education, which supports the health literacy journey of Māori children and their whānau.

- Invest in regular in-service training for staff on asthma best practice.
- Utilise GP patient management systems to provide longitudinal asthma education monitoring.
- Develop asthma training packages for patients, whānau and communities.
- Nominate a staff member to the role of ‘asthma champion’ with responsibility for leading uptake of best practice guidelines, resource implementation and quality assurance monitoring.
- Include the populations served in the design, implementation and evaluation of health information and services.

Health Professionals

Health professionals need to be able to provide up-to-date best-practice asthma care for Māori children, taking account of the: age; severity; existing knowledge; learning styles; and cultural preferences of the child and their whānau. All children with asthma should have clear, individualised asthma plans, with strategies that encourage health promotion, self-management and disease prevention.

- Maintain a high level of competency in current best practice for the management of childhood asthma.
- Ensure all children have access to individualised, understandable asthma action plans.
- Follow a step-wise education plan when providing asthma support to Māori patients.
- Provide updated electronic access to asthma plans for whānau, community health workers and schools.
- Routinely utilise specialist (medical and/or nursing) respiratory and paediatric expertise to effectively manage those whānau with complex health-care needs.
2. Whakaakoako (Teaching Strategies)

Health System

The health system needs to recognise and promote the importance of health literacy and chronic disease management competencies for all health professionals and other health-care workers involved in asthma management.

- Influence medical, nursing and pharmacy schools and other health training programmes to teach health literacy and chronic care management to students.
- Establish and monitor competencies for all health professionals in health literacy education and chronic disease management.
- Set an expectation within health policies and strategies that all health services will deliver high-quality care that focuses on meeting the health needs and aspirations of Māori children with asthma.

Health Organisations

Health organisations need to work collaboratively with Māori communities to develop high-quality asthma resources and to incorporate these into their educational strategies. Innovative, flexible and community-based asthma educational approaches need to be adopted to better meet the needs of Māori whānau.

- Work collaboratively with children with asthma to develop high-quality asthma resources for a range of ages and levels of asthma knowledge – particularly interactive and/or audio-visual resources, and resources specifically for Māori children.
- Develop longitudinal asthma education support and monitoring tools for patients/whānau.
- Develop community-based health literacy asthma support and education sessions that are culturally appropriate for Māori children and whānau.

Health Professionals

Health professionals’ teaching strategies need to engage the whānau according to their needs and learning preferences, empowering them to have the confidence to manage their child’s asthma. This involves a requirement for health professionals to undertake specific training in health literacy-based education techniques, chronic disease management education strategies, and cultural engagement.

- Ensure all consultations are seen as opportunities to build health literacy, promote patient activation and support asthma self-management.
- Undertake specific training in the use of health literacy-based education techniques.
- Regularly incorporate a variety of learning media (e.g. interactive/tactile/audio-visual asthma resources) to support asthma education.
- Continue to develop cultural competency skills for engaging with Māori children and whānau.
3. Whakawhanake (Workforce Development)

**Health System**

The health system must develop a range of health-care personnel equipped to meet the specific challenges of providing chronic disease management for Māori children with asthma. Coordinated development of inter-professional strategies is needed, along with recognition of the roles that asthma educators, pharmacists, non-professional health-care workers, community organisation staff and trained volunteers can have in supporting the provision of holistic, integrated asthma care.

- Explore models of integrated care to promote closer working relationships between health professionals, and enhanced inter-professional learning opportunities.
- Improve role delineation for health professional groups in the chronic disease management of asthma in support of a multidisciplinary support approach.
- Formalise and expand scopes of practice for other health worker roles (such as asthma educators, pharmacists and community health workers) to support the provision of holistic integrated asthma care.

**Health Organisations**

Effective asthma care requires a team approach. Health organisations need to develop and adopt policies and procedures that encourage better interdisciplinary harmonisation and strengthen links with other providers to address the dynamic and holistic well-being of Māori children with asthma. Health organisations must also ensure all staff understand and practise effective ways of engaging with Māori in clinical settings.

- Provide policies and procedures for cross-disciplinary harmonisation of asthma management and education.
- Develop collaborations and provider networks (e.g. within and between DHBs, PHOs, Māori providers, NGOs and other community agencies) to support implementation of best practice for asthma and chronic care management approaches.
- Mandate the inclusion of cultural competency across the organisation to ensure all staff understand effective ways of engaging with Māori in clinical settings.

**Health Professionals**

Health professionals must prioritise the establishment of regular, consistent, trusted relationships with patients, to build a shared understanding of values, priorities and management strategies. Health professionals need to establish collaborative relationships with colleagues and community organisations to coordinate activities and ensure that asthma education is consistent, timely and comprehensive.

- Maintain continuous high-quality relationships to build long-term trust relationships with patients.
- Routinely explore the manageability of asthma management plans and utilise relevant support services to address identified barriers.
- Develop collaborative partnerships with Māori health providers, Whānau Ora providers and other community-based organisations in support of asthma care for Māori children.
4. Te Anga (Model of Care)

Health System

The current system based around reactive, episodic care is failing Māori children with asthma, and is manifesting in significant inequalities in asthma health outcomes. The health system urgently needs to implement a chronic care management model to provide proactive, longitudinal, patient/whānau-centred, culturally responsive care to Māori children with asthma within a multidisciplinary team environment.

- Implement a systematic chronic care management model for asthma care to provide long-term, proactive, whānau-centred, multidisciplinary support.
- Develop and support shared information platforms allowing integration of asthma support and monitoring between providers.
- Align provider incentives so that proactive chronic disease management efforts are rewarded.
- Allow flexibility within Care Plus eligibility criteria to include asthma as a single qualifying condition.
- Fund a free annual asthma review in primary care.

Health Organisations

Health Organisations need to adopt a proactive chronic care management approach to all aspects of asthma support and integrate health literacy policies and procedures into the organisational culture so that every asthma interaction aligns with effective learning outcomes.

- Develop and implement health literacy policies and procedures for staff.
- Adopt a proactive chronic care management approach to all aspects of asthma support within organisational policies and procedures.
- Incorporate a philosophy of culturally competent holistic care into organisational policies and individual consultations with Māori.
- Contribute to the generation of evidence-informing initiatives to activate whānau and build asthma self-management capabilities.

Health Professionals

Māori children with asthma face significant barriers to effective asthma management. It is imperative that health professionals recognise the contribution of structural barriers within health care that contribute to poor health outcomes, and ensure all their patients are receiving eligible supports and benefits.

- Routinely incorporate chronic care management approaches into asthma consultations, including proactive strategies to provide preventive advice when patients are well.
- Ensure follow-up visits are provided subsequent to acute presentations/hospitalisation.
- Provide access to asthma self-management support after-hours via the internet or telephone.
- Ensure all children with asthma are offered support packages when eligible (e.g. Care Plus, Disability Allowance, Whānau Ora services).
PART 1: INTRODUCTION

Purpose

He Māramatanga Huangō: Asthma Health Literacy for Māori Children was a research project funded by the Ministry of Health and the Asthma Foundation of New Zealand. The project was designed to inform health sector policy, service and resource development through the following specific objectives:

1. examine the health literacy demands on both whānau (family) and health providers regarding asthma management
2. investigate and identify health literacy barriers, and facilitators
3. identify gaps in and issues with asthma health literacy skills and knowledge
4. make recommendations to improve health literacy, in order to improve asthma outcomes for Māori children (tamariki).

The project was led by the University of Otago in collaboration with researchers from Tu Kotahi Māori Asthma Trust, in Seaview, Lower Hutt, and the Workbase Education Trust, a New Zealand provider of workforce literacy development. A project advisory group provided advice throughout the project and reviewed the report. The advisory group consisted of the following members: Sharon Cavanagh, Angela Francis, Dr Kura Horsfall, Stephen Lungley, Raukura Maxwell, Dr Kyle Perrin, Paula Searle and Dr Pat Tuohy. This document describes the mixed-methods approach used for the project and the final results, along with recommendations for improvements.

Background

What is Asthma?

Asthma is a long-term condition of the lungs where there is inflammation of the airways through which a person breathes (i.e. the lining becomes swollen and irritated). Inflamed airways become over-reactive, and the muscles around the airways tighten to make them narrower. Inflammation also produces thick mucus that can block the airways. It is this repeated airways narrowing and mucus production that leads to the common asthma symptoms of wheezing, difficulty breathing and coughing (especially at night).

The primary cause of asthma – why some people get asthma and others do not – is not known. However, there are many factors known to contribute to the development of asthma, including genetic and environmental factors. Once asthma has developed, increases in asthma symptoms may occur because of exposure to various ‘triggers’ such as viral infections, exercise, allergens, irritants, or due to unknown causes. For the majority of children asthma can be controlled most of the time by using the right medication and avoiding triggers. The mainstay of medication involves inhalers, which when used with a spacer device ensure that the medication is inhaled directly into the lungs. Reliever inhalers (e.g. short-acting beta agonists) relax and open the airways, while preventer inhalers (e.g. inhaled corticosteroids) reduce the underlying inflammation.

The Impact of Asthma

Asthma affects a significant proportion of New Zealand children, with rates amongst the highest in the world. Over 26% of children report symptoms and one in seven children (14%) takes medication for doctor-diagnosed asthma. The prevalence of asthma is significantly higher amongst Māori: 28.5% of Māori children experience current asthma symptoms compared with 20.7% of European/Pākehā children. After adjusting for age and sex differences, Māori children are 1.5 times more likely be using medication for asthma as non-Māori.

The burden to children who are affected by asthma is considerable. Twelve percent of children with asthma miss school each month, and 14% attend an emergency department or are admitted to hospital with asthma each year. The impact on quality of life is also significant, especially in younger individuals. Asthma results in the loss of 15,084 disability-adjusted life years (DALYs), with approximately 27%
occurring in individuals aged less than 20 years. Despite modern treatment, asthma in New Zealand continues to exceed one death per week (on average) and account for over 2,500 hospitalisations per year in children and adolescents (Figure 2). New Zealand has the highest death rate from asthma amongst high-income countries. The medical and economic costs of asthma in New Zealand are estimated to be over $800 million per year.

The New Zealand-based Patient Outcomes Management Survey (POMS) study, which aimed to investigate the magnitude of morbidity from asthma within the New Zealand population, revealed that 90% of children with asthma were sub-optimally controlled and 42% were not well controlled. Among those children with asthma that was not well controlled, 71% were receiving inadequate treatment. The study also noted a striking mismatch between the perception of asthma control and the actual level of control, with 76% of those children thinking that their asthma was well controlled and 85% being satisfied with their level of control.

Figure 2: Asthma hospitalisations, by age group and ethnicity, 2011

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total</th>
<th>Māori</th>
<th>% of Total</th>
<th>Non-Māori</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–4 years</td>
<td>2624</td>
<td>1021</td>
<td>38.9%</td>
<td>1603</td>
<td>61.1%</td>
</tr>
<tr>
<td>5–14 years</td>
<td>1832</td>
<td>674</td>
<td>36.8%</td>
<td>1158</td>
<td>63.2%</td>
</tr>
<tr>
<td>15–24 years</td>
<td>817</td>
<td>321</td>
<td>39.3%</td>
<td>496</td>
<td>60.7%</td>
</tr>
<tr>
<td>Total (0–24 years)</td>
<td>5273</td>
<td>2016</td>
<td>38.2%</td>
<td>3257</td>
<td>61.8%</td>
</tr>
</tbody>
</table>

Standardised Rates. All admissions (ICD-10: J45, J46) 2011. New Zealand Health Information Service, Ministry of Health

Inequalities in asthma outcomes for Māori children are striking: Māori children have a greater prevalence of severe asthma than European children and are more likely to require days off school for asthma-related illness. The admission rate for Māori remains nearly three times higher than for non-Māori. Also, despite higher prevalence of disease and severity of symptoms, Māori children are dispensed fewer preventive treatments, resulting in poorer overall asthma control. Māori are less likely to have a peak flow meter or asthma action plan, and fewer are prescribed regular inhaled corticosteroids. Caregivers of Māori and Pacific children report lower rates of receiving easy-to-understand education about asthma and action plans than caregivers of non-Māori, non-Pacific children.

While the prevalence of asthma has decreased for New Zealand European children over the past few decades, this reduction has not occurred for Māori. Clear recommendations for strategies to reduce these disparities have been available since a ministerial review of Māori asthma, ‘He Mate Huangō’, was commissioned in 1991, yet many of these recommendations remain unimplemented. Addressing the burden of childhood asthma for Māori is a critical issue warranting urgent action.

Health Literacy

Initially the term ‘health literacy’ was understood to refer to something patients could or could not do with regard to their health and it was defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions.” Superficially this definition appears to fall into the category of health literacy as an individual skill set. However, implicit in this definition is the need for the health system to not merely present information in accessible ways, but also to engage with individuals to make sure they can access, understand and act on the information they receive.

More recently it has been argued that if health literacy is the ability to function in a health-care environment, then health literacy must rely on aspects of both the individual and other parties involved in communication, as well as those designing health services. Health literacy emerges when the “expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services.” This definition sees health literacy as a dynamic state reliant on factors including the medical condition, the health-care provider and the health system.

Where the health literacy required in managing a health condition is greater than the existing skills and knowledge of a patient or family, health professionals have a role in reducing any unnecessary health
literacy demands. They also have a role in helping patients and families to build their health literacy in order to effectively manage their health.\textsuperscript{21,32,33} Recent research has highlighted a chasm separating what health professionals intend to convey in written and spoken communication and what patients actually understand.\textsuperscript{22} This mismatch has previously been viewed as a patient deficit issue caused entirely by patients lacking health skills and knowledge, despite being given all the necessary information by health professionals.\textsuperscript{22} Recent evidence now recognises health literacy as a dynamic systems issue reflecting the complexity of health information being presented and the health-care system being navigated.\textsuperscript{19,20}

\textit{A Learning Framework}

Bloom’s Taxonomy of Learning Domains (Figure 3) is a schema or organisational concept which identifies the multi-level forms of aptitude required for critical thinking that can be applied to a health literacy framework using skills such as analysing and evaluating, rather than just remembering facts.\textsuperscript{24} This framework classifies objectives in terms of explicit or implicit intellectual skills and abilities and includes three categories that make up the learning process: knowledge (knowing), attitude (feeling) and skills (doing). A revised version, reflecting a more active form of thinking, helps us to understand where individuals are in the learning process.\textsuperscript{35}

A broader conceptualisation acknowledges that health literacy comprises a wide range of skills and competencies that people develop over a lifetime in order to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.\textsuperscript{36} The term also encompasses skills and knowledge unique to health, such as a conceptual understanding of how the body works, knowing when and where to seek health advice, being able to evaluate the appropriateness of health advice, being able to interpret and describe health symptoms, as well as acting with confidence in a health setting.\textsuperscript{21,33,36}

Experts emphasise the complex, social and changing nature of health literacy by defining it as a “multi-dimensional construct that develops over time, across different health contexts and through social interactions”.\textsuperscript{32} Health literacy develops along a continuum towards greater knowledge, greater self-management and greater participation in decision-making, with health literacy seen as both a process and an outcome. While there is a clear need to adopt more theory-based understanding of text structures and functions, there are other powerful constructs, including cultural appropriateness, relevance and context, that are needed to close the gaps between health messages, health messengers and patients.\textsuperscript{37}

\textbf{Figure 3: Bloom’s revised taxonomy}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{blooms_taxonomy.png}
\caption{Bloom's revised taxonomy}
\end{figure}
A comprehensive view of health literacy can include many or all of the following: the ability to understand scientific concepts, content and health research; skills in spoken, written and online communication; critical interpretation of mass media messages; navigating complex systems of health care and governance; and knowledge and use of community capital and resources, as well as using cultural and indigenous knowledge in health decision-making. This view sees health literacy as a social determinant of health that offers a powerful opportunity to reduce inequities in health.

**Health Literacy as a Determinant of Health**

Poverty, poor housing conditions, environmental factors and inadequate access to health care services have been well described as determinants of health, and of particular importance to asthma. More recently, health literacy has emerged as an influential social determinant having an impact across the health spectrum. As the sphere of health continues to grow and become more complex, the relationship between the health system, health professionals and the consumer also continues to change and evolve. Health literacy is a concept that lies at the centre of this evolving relationship.

The 2006 *Kōrero Mārama: Health Literacy and Māori* report highlighted that, on average, New Zealanders have poor health literacy skills, with both Māori and non-Māori scoring below the minimum required level for individuals to meet the complex demands of everyday life and work. Strikingly, four out of five Māori males and three out of four Māori females have poor health literacy skills (Figure 4).

**Figure 4: Distribution of health literacy for Māori and non-Māori in NZ, by gender, 2006**

**Health Literacy, Children & Asthma**

Complex medical conditions such as asthma, with wide-ranging treatment options and service provision, as well as an array of communication channels, have a greater impact on health literacy demands for patients and families. Consequently, system-level changes are needed at both the health professional and health organisational levels for the health literacy issue to be addressed.

Low parental or caregiver literacy has been shown to be related to worse health outcomes, particularly for young children, with inadequate literacy strongly correlated with poorer knowledge of asthma and improper inhaler use. Internationally there have been few intervention studies to improve child health outcomes for children or parents with low literacy. However, in a recent longitudinal intervention addressing literacy and asthma self-management skills, minority children whose reading improved the most were least likely to have repeat emergency department visits and hospitalisations compared with non-minority children.
A longitudinal qualitative study involving Māori parents and children with asthma exploring their experiences highlighted the considerable burden of asthma-related demands faced by Māori parents and children. Parents also noted significant complexities in engaging with the health-care system, particularly with respect to their management and interactions with health providers. Whānau from this study expressed a clear aspiration for better asthma services that would enable them to develop asthma skills in a mana (prestige)-enhancing way while building their knowledge, capacity and resilience. Overall, the findings from that study provided important evidence for the need to develop more effective approaches to educating and engaging with Māori whānau with asthma.
PART 2: METHODS
PART 2: METHODS

Methodology

Kaupapa Māori Research (KMR) principles guided this research and ensured Māori protocols were followed throughout the research processes. KMR prioritises Māori cultural values and systems, while ensuring interpretations remain focused on benefiting health outcomes for Māori. Treaty of Waitangi principles were incorporated into a partnership approach with Māori participants and local Māori health provider Tu Kotahi Māori Asthma Trust using the Whānau Tuatahi (Family First) framework developed as part of a previous research study. This framework is a mechanism for the practical adaptation and application of Westernised research methods within a kaupapa Māori methodology. This translational framework was shaped by the following concepts: whakawhirinaki (trust), ngāwari (flexibility), whakawhanaungatanga (building relationships), whakamana (empowerment), utu (reciprocity) and hurihuringa (reflexivity). These concepts have been previously validated with Māori parents, children and whānau.

Qualitative and quantitative methodologies were used to capture a comprehensive and diverse range of perspectives. The study was conceptualised to address four distinct components (Figure 5).

Figure 5: Conceptual diagram outlining the four main components of the study

The aim was to use a health literacy lens to explore the perspectives of health professionals and whānau (Māori parents/caregivers and children) in relation to the ideals of giving (or receiving) asthma knowledge, versus the practical capacities to deliver (or receive) these messages. The focus was not only on what asthma knowledge was involved, but also other critical elements that have an impact on its delivery, including who delivers it, when and how it is delivered, and why that approach is used.

Methods

In this section we present the specific methods used to investigate asthma health literacy within the above-mentioned contextual framework. Figure 6 shows an overview of the different methods employed to investigate each component (colour-coded per the components identified in Figure 5). Each method will then be detailed in turn.
In order to generate a definitive viewpoint on the range of knowledge demands involved with asthma management, an Asthma Expert Panel was convened, consisting of 14 health professionals from a range of health disciplines involved in the provision of care to children with asthma. The panel included: Four paediatricians, one adolescent physician, one respiratory physician, two general practitioners, one paediatric respiratory physiotherapist, one pharmacist and one respiratory nurse.

The panel were asked to produce a comprehensive list of the asthma demands (including knowledge, skills, roles and tasks) deemed necessary for the optimal management of childhood asthma. This list was used to scope the range of topics addressed in subsequent components of the study, and served as the basis for the domains discussed in the card-sort exercise and whānau interviews.

A modified Delphi approach was used to assemble the list, with each member of the panel independently submitting anonymised input. This input was collated into a single list and re-sent for commentary, refinement, further additions and modifications. All panel members were able to see the anonymised commentary of the other panel members. Three rounds of electronic input were conducted. No weighting or prioritisation was applied to the demands list.

To capture a wide range of health professional viewpoints and increase the generalisability of findings, an online survey using Survey Monkey was sent nationally to health professionals involved with the asthma care of children/youth. The survey explored their health literacy practices in delivering asthma services, and their perspectives on barriers to optimal asthma care.

The survey was sent electronically to health professionals identified as having a potential role in paediatric asthma via the Medidata email database. Medidata is a division of the MIMS (NZ) Ltd group – the professional health-care publisher in New Zealand which maintains a database of all registered health professionals. Only health professionals who have authorised Medidata to make electronic contact were included. All professions are classified within predefined database categories. In order to maximise efficiency, and minimise responder inconvenience and cost, the category was included only if the majority of professionals within that classification were likely to be involved with the routine management of childhood asthma (e.g. physiotherapists were excluded on this basis). Health professionals from the following professions/sub-professions (as primary or secondary profession) were included:

- doctor – general practice (accident & medical; general practitioner; GP Training Programme; locum; surgery locum)
• doctor – specialist/consultant (emergency medicine; respiratory physician; paediatrician)
• doctor – hospital non-specialist (accident & medical; medical officer special state; registrar)
• nurse (primary care/ community)
• pharmacist (head pharmacist; retail locum pharmacist; retail pharmacist)
• professionals (asthma educator).

In order to reduce respondent bias and derive denominator data, no additional enrolment sources were utilised. Each eligible survey respondent was sent an initial email invitation, followed by two reminder requests. All communication with respondents was conducted by Medidata.

**Health Professional Respondent Profile**

The survey was despatched by email to 2784 health professionals (Figure 7). The survey was completed by 865 health professionals (total response rate 31%) from all 20 district health board (DHB) regions. Of these, 806 reported providing asthma services for children under 18 years and/or their parents or caregivers, and hence were eligible to complete the survey. NB: Only those health professional respondents who were ‘eligible’ completed demographics and role description questions. Of the 806 eligible health professionals, 45% were GPs, 8% hospital doctors, 33% nurses, 7% pharmacists and 7% asthma educators.

Health professionals’ self-reported ethnicity (prioritised, level-one output) was as follows: 37 (4.6%) Māori, 19 (2.4%) Pacific Island, 74 (9.2%) Asian, 518 (64.3%) Other, 158 (19.6%) no response recorded.

**Figure 7: Health Professional Survey response rates, by profession**

<table>
<thead>
<tr>
<th>Professional Category</th>
<th>Total Invites</th>
<th>Eligible Responses</th>
<th>Response Rate</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor (General Practice)</td>
<td>1522</td>
<td>365</td>
<td>24.0%</td>
<td>45.3%</td>
</tr>
<tr>
<td>Doctor (Specialist/Consultant)</td>
<td>143</td>
<td>48</td>
<td>33.6%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Doctor (Hospital Non-Specialist)</td>
<td>73</td>
<td>18</td>
<td>24.7%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Nurse (Primary Care/ Community)</td>
<td>785</td>
<td>264</td>
<td>33.6%</td>
<td>32.8%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>201</td>
<td>54</td>
<td>26.9%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Asthma Educator</td>
<td>60</td>
<td>56</td>
<td>93.3%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Not specified</td>
<td>0</td>
<td>1</td>
<td>-</td>
<td>0.1%</td>
</tr>
<tr>
<td>Total</td>
<td>2784</td>
<td>806</td>
<td>29.0%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Sampling Biases**

Potential biases included:

1. selection biases: consent for email solicitation from Medidata; differential relative size of profession workforce; relevance of the survey topic to the professional group (group selection); cost
2. response biases: workload/time constraints; access to email; motivation/ relevance to work; value of incentive (iPad mini)
3. misclassification bias: response categories were derived from Medidata categories; however, respondents may have classified themselves differently in the survey to how they did in the Medidata response form.

**Provider Qualitative Interviews**

To complement this survey and provide in-depth information regarding barriers and facilitators to health literacy in a real-world context, we conducted a number of semi-structured interviews with health provider staff. Five providers were selected using opportunistic purposive sampling to comprise a mix of mainstream and Māori providers, and diversity of size of practice and location (Greater Wellington and...
Auckland regions). We also selected practices where one of the project team or advisory group had a staff contact/network to broker contact, facilitate recruitment and foster active engagement.

As part of these interviews a variety of practice staff were interviewed to identify where, when, who and how asthma education was delivered, what topics were discussed, and staff perceptions of barriers/facilitators to effective asthma health literacy for Māori children. A total of 35 staff were interviewed across the five practices. Practice staff (novice and expert) were identified as having the following roles: nurses, GPs, pharmacists, community health workers and managers.

A semi-structured interview schedule was developed using open-ended questions framed around the research aims and was kept flexible enough to allow participants to focus on what they deemed important. All interviews were audio-taped and transcribed verbatim, with identifying details removed. Ethics approval was obtained from the Health and Disability Ethics Committee (ref: 13NTB26). All participants were given a full verbal and written explanation of the study and then asked for written consent prior to their participation.

Qualitative analysis was undertaken using a phenomenological approach whereby participants’ experiences were explored in order to gain an understanding of their perspectives on managing asthma. Initial coding was undertaken on a line-by-line basis by two investigators using ‘open coding’ to allow multiple codes to be applied to single segments of data. Subsequent re-reading and coding of the data were conducted in order to incorporate findings in an iterative fashion. Sub-themes identified in initial coding were further developed and aggregated into main themes through subsequent iterations of coding. A reflexive process incorporated a te ao Māori view in order to ensure the analysis reflected a Māori perspective.

**Whānau**

**Whānau Interviews / Focus Groups**

Twenty semi-structured interviews and a focus group were held with Māori parents and their children aged 4–18 years who had asthma. These interviews were informed by a qualitative descriptive design, with a semi-structured interview schedule used for the in-depth interviews to prompt further discussion when needed. The interview locations and processes were selected to ensure participants were able to convey their stories in a culturally appropriate manner that upheld the mana (prestige) of the participants, while avoiding testing their knowledge and allowing for open, non-judgemental discussions.

To complement the qualitative interviews, these same parents and children were asked to complete a ‘whānau asthma profile’ consisting of a brief asthma severity questionnaire.

**Characterisation of Participants (Whānau Asthma Profiles)**

**Child Characteristics**

Figure 8 shows the demographics and asthma status of the 20 index Māori children (tamariki) who were interviewed as part of the study. An additional seven whānau members were interviewed as key informants in support of those interviews.

The median age was 14.1 years, with ages distributed between 4 and 18 years old (a range of 14 years). The median age at which the child/parent believed asthma first developed was 2.0 years old, with age of onset ranging from birth to 11 years.

Twelve (60%) of the children had ever been admitted to hospital for asthma, with seven (35%) having been admitted in the preceding 12 months. Fifteen (75%) children had experienced wheezing attacks in the last 12 months, with four (20%) having had more than 12 attacks. Of the 14 children who had experienced these wheezing attacks, 10 (50%) of them experienced wheezing that was severe enough to limit their speech to only one or two words at a time between breaths.

‘Colds or flu’ were the most commonly identified factor associated with worsened symptoms, with 15 (75%) saying it made their wheezing worse. Other identified triggers were (in decreasing order of prevalence): ‘weather’ (55%); ‘other (e.g. exercise)’ (45%); ‘dust’ (45%); ‘pollen’ (40%); ‘cigarette smoke’ (30%); ‘emotion’ (20%); ‘pets’ (20%); and ‘foods or drinks’ (10%).
## Child Asthma Characteristics (N = 20)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Index Child Demographics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years: median (range)</td>
<td>14.1</td>
<td>(4–18yrs)</td>
</tr>
<tr>
<td>Age first developed asthma: median (range)</td>
<td>2.0</td>
<td>(0–11 yrs)</td>
</tr>
<tr>
<td><strong>Hospitalisation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever hospitalised for asthma?</td>
<td>12</td>
<td>(60%)</td>
</tr>
<tr>
<td>Times admitted to hospital in the past 12 months:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>13</td>
<td>(65%)</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>(15%)</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>(15%)</td>
</tr>
<tr>
<td>3+</td>
<td>1</td>
<td>(5%)</td>
</tr>
<tr>
<td><strong>Asthma Severity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attacks of wheezing in the past 12 months:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>(25%)</td>
</tr>
<tr>
<td>1–3 attacks</td>
<td>7</td>
<td>(35%)</td>
</tr>
<tr>
<td>4–12 attacks</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>&gt; 12 attacks</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>Speech-limiting wheeze in last 12 months?</td>
<td>10</td>
<td>(50%)</td>
</tr>
<tr>
<td>What has made your wheezing worse?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weather</td>
<td>11</td>
<td>(55%)</td>
</tr>
<tr>
<td>Pollen</td>
<td>8</td>
<td>(40%)</td>
</tr>
<tr>
<td>Emotion</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>Dust</td>
<td>9</td>
<td>(45%)</td>
</tr>
<tr>
<td>Pets</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>Colds or ‘flu</td>
<td>15</td>
<td>(75%)</td>
</tr>
<tr>
<td>Cigarette smoke</td>
<td>6</td>
<td>(30%)</td>
</tr>
<tr>
<td>Foods or drinks</td>
<td>2</td>
<td>(10%)</td>
</tr>
<tr>
<td>Other (e.g. exercise)</td>
<td>9</td>
<td>(45%)</td>
</tr>
<tr>
<td><strong>Asthma Maintenance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a peak flow meter at home?</td>
<td>15</td>
<td>(75%)</td>
</tr>
<tr>
<td>Do you have a written asthma plan?</td>
<td>11</td>
<td>(55%)</td>
</tr>
<tr>
<td>Ever prescribed oral steroids for asthma?</td>
<td>13</td>
<td>(65%)</td>
</tr>
</tbody>
</table>

Peak flow meters were present at the homes of 15 (75%) children. Only 11 (55%) of the children had written asthma plans. Thirteen (65%) of the children had been prescribed oral corticosteroids for their asthma at some time.

Figure 9 shows the current asthma medication treatment step of each of the children interviewed. The figure also compares these children with national dispensing data for children, by ethnicity.\(^\text{10}\) Five children (25%) were on step 1 (i.e. short-acting beta-2 agonists alone). Two of these (40%, or 10% overall) had also required a course of oral corticosteroids. Fifty percent of children were on step 2 (i.e. a short-acting beta-2 agonist in combination with an inhaled corticosteroid). Twenty-five percent were on step 3 (i.e. step 2 medications with additional controller medications such as a long-acting beta-2 agonist).
Mild, intermittent asthma – SABA alone
Children with symptomatic asthma should be prescribed short-acting beta-2 agonists (SABA) such as salbutamol or terbutaline. Māori and Pacific children have a greater frequency of severe asthma than children of other ethnic groups, and may benefit from more intensive initial treatment than step 1.

SABA alone + oral corticosteroids
Children prescribed SABA alone, but who have needed oral corticosteroids. This category is a sub-group of step 1. It reflects a group of children who were potentially not receiving adequate preventive therapy.

More severe asthma, or symptoms uncontrolled – SABA and ICS
The addition of inhaled corticosteroids (ICS) may be beneficial for children whose symptoms are uncontrolled on step 1 or whose asthma symptoms are more severe.

Control not achieved at step 2 – add LABA
If control is not achieved with a SABA and ICS then additional treatment will be needed. For children aged 5–12 years a long-acting beta agonist (LABA) should be considered.

The prevalence of children requiring treatment step 2 is very similar to the national data for asthma medication amongst Māori children. The proportion of children requiring step 3 regimes is considerably higher than for any ethnic group nationally. This may reflect either higher severity, or higher uptake of long-acting beta-2 agonists among the children surveyed. Also of note is the proportion of those children on step 1 who have also required oral corticosteroids (i.e. potentially under-treated) (11%), although this too is lower than the national average for Māori and equivalent to the national data for European/Other populations.
Parent/Caregiver Characteristics

Figure 10 shows the characteristics of the 20 parents/guardians interviewed along with their children. Amongst the parents/guardians of the index children, 13 of the 20 (65%) interviewed had no secondary school qualification. Four (20%) had achieved NCEA (National Certificate of Educational Achievement) level one or equivalent. One (5%), had achieved NCEA level two or equivalent and two (10%) had NCEA/National certificate level three or equivalent. Thirteen (65%) of the children had at least one parent who had asthma, eczema or hay fever. Asthma was present in 8 (40%) of the mothers while 11 (55%) had an atopic condition (i.e. at least one of these three conditions: asthma, eczema or hay fever). Five (25%) of the fathers had asthma: three (15%) of these five also had concomitant hay fever or eczema as well as asthma.

Figure 10: Whānau Asthma Profile: parent/caregiver characteristics

<table>
<thead>
<tr>
<th>Parent/Caregiver Characteristics (N = 20)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Secondary School Education:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No NZ qualification</td>
<td>13</td>
<td>(65%)</td>
</tr>
<tr>
<td>NCEA level 1 or equivalent</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>NCEA level 2 or equivalent</td>
<td>1</td>
<td>(5%)</td>
</tr>
<tr>
<td>NCEA level 3 or equivalent</td>
<td>2</td>
<td>(10%)</td>
</tr>
<tr>
<td><strong>Parental Asthma &amp; Atopy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother has asthma</td>
<td>8</td>
<td>(40%)</td>
</tr>
<tr>
<td>Mother has asthma, eczema or hay fever</td>
<td>11</td>
<td>(55%)</td>
</tr>
<tr>
<td>Father has asthma</td>
<td>4</td>
<td>(20%)</td>
</tr>
<tr>
<td>Father has asthma, eczema or hay fever</td>
<td>5</td>
<td>(25%)</td>
</tr>
<tr>
<td>Mother or father has asthma, eczema or hay fever</td>
<td>13</td>
<td>(65%)</td>
</tr>
</tbody>
</table>

Whānau Asthma Health Literacy Status (Card-Sort Exercise)

Children were asked to self-evaluate their asthma knowledge using a ‘card-sort’ exercise. Such exercises are a simple, effective way for younger people to complete a Likert scale response question in a fun, non-threatening manner that is visual, tactile and interactive.

Each knowledge item was clearly described individually on coloured cards, which were presented to the child in a stack for sequential rating. Likert response options were represented on larger coloured cards arranged across the desk or table in front of the participant in logical rank order. Children were offered an introductory explanation for the exercise as follows:

“We are interested in finding out what Doctors and Nurses are telling people about their/their child's asthma. On these cards are a whole bunch of things that you may or may not have been told about asthma. Please can you help us out by sorting these cards into piles, to work out what you remember having been told?”

The instructions intentionally used colloquial vocabulary familiar to the children, and emphasised the concept of what they ‘remembered having been told’ rather than ‘knowledge’ to de-emphasise the perception of being tested.
The following response options were provided (the number represents the corresponding ordinal scale value):

1. I know **NOTHING** about this
2. I know **VERY LITTLE** about this
3. I know **SOMETHING** about this
4. I know **MOSTLY** about this
5. I know **COMPLETELY** about this.

Children were then supported to self-evaluate their knowledge using the five-point Likert response scale by physically placing the knowledge item card onto the table below the appropriate response option card. An investigator recorded the ordinal value corresponding to the respective response option on a separate response sheet. Older children (>12 years old) independently completed the exercise based on their own evaluation of their knowledge. In younger children (≤12 years old) the exercise was completed by the parent, with input from their children.

Thirty-one knowledge categories were investigated. These knowledge categories were obtained directly from the list of asthma demands derived by the Asthma Expert Panel. The items were then adapted to lay language for improved readability.

**Qualitative Validation**

At the conclusion of the card-sort exercise, the sorted piles were used as discussion points to introduce the qualitative components of the interview.

For each item in the ‘completely’ or ‘mostly’ piles, the interviewer asked the following questions:

1. How did you learn about this?
2. Did anyone talk to you about this? (Who? When was that? Where did that happen?)
3. Did you read about this anywhere (in a book, brochure or on the internet)? Where from?

**Resources**

**Resource Review**

Written resources were reviewed according to criteria derived from the Ministry of Health guidelines and those developed by the Workbase Education Trust.\(^5\),\(^6\) Resources for review were collected from a number of general practices, pharmacies, websites and other online sources, and those supplied by the Asthma Foundation. We accessed online resources to replicate what whānau might do if they were searching for information about asthma.

The review included the following evaluation criteria:

1. whether there was a clear or implied purpose
2. the specified or implied audience of the resource
3. the resource type
4. the access point (i.e. where on the care pathway the resource would be accessed)
5. the vocabulary and general readability
6. language and text features; for example, layout, white space as well as use of visuals (helps create contextual meaning)
7. inclusion of Māori concepts and values.

An evaluation report was produced for each resource, and the findings were then amalgamated and synthesised into a single summary report.
Methodological Strengths & Limitations

Core strengths of this research project included the kaupapa Māori methodological approach and the Māori community partnerships which yielded significant community and health sector buy-in, while also protecting the mana and integrity of the research participants.

The timeframe and budget of the project defined the scope of the enquiry; however, logistical efficiencies (purposive sampling of practices, online survey, etc.) and the mixed-methods approach allowed the team to overcome the inherent restrictions of each method. This enabled the generalisation of national survey results combined with the richness and depth of qualitative interviews.

As with all research, recruitment bias was a potential hazard. We took steps with the survey to capture denominator data in order to permit calculation of the response rate. Similarly, with the qualitative interviews we attempted to interview all (or as many as possible) staff at the selected practices to minimise this effect. However, it should be noted that those practices and whānau that consented to participate were invariably more proactive and supportive of the purpose of the study than those who declined.
PART 3: FINDINGS
PART 3: FINDINGS
This part details the results obtained from each of the methods, presented sequentially.

Asthma Expert Panel

Health Provider – Ideals & Expectations

Asthma Demands
After several rounds of review the expert panel compiled a list of asthma-specific knowledge demands. The comprehensive list included a vast array of knowledge and skills the panel felt were necessary for a child and their parent/caregiver to understand in order to effectively manage the child’s asthma. Figure 11 shows the major category headings under which these knowledge demands were grouped.
In addition to the large array of asthma-specific knowledge demands, managing asthma (as with any chronic illness) has generic health literacy demands which require skills needed for accessing health-related services and for navigating health-care systems. These demands include filling out forms, reading signs, understanding the support services and benefits available, interpreting rights and responsibilities, and evaluating (the value and reliability of) health information. Parents are also required to be able to read medicine labels; follow directions for administering medications; use medication delivery devices; recognise and monitor signs and symptoms; talk to health professionals in an informed and informative manner; and make critical decisions when the asthma is worsening.

Knowledge represents only the base level of Bloom’s taxonomy (Figure 3) pyramid. One also needs to be able to pull these knowledge threads together, make sense of them, apply them to other contexts, evaluate the evidence for each, and know when one needs to get further help. The level of knowledge and skills identified within each of the categories shown in (Figure 11) requires the parent/caregiver to access all six domains on Bloom’s taxonomy in order to optimally manage their child’s asthma.

As an indicative example, for a parent/child to effectively administer a medication for a child that has asthma (e.g. reliever inhaler for wheezing) they need the following.

**Knowledge:** Disease-related: anatomy of the lungs; physiology of breathing; pathology and pathophysiology of asthma; causative, aggravating and relieving factors; symptoms; clinical signs; differential diagnosis; indicators of severity; life-threatening signs; monitoring techniques. Medication-related: name of medications, medication types, purposes, doses, frequencies, routes, side-effects, contraindications, storage, delivery/administration devices, care/maintenance, and supply/resupply.
**Understanding:** Identify which knowledge is relevant, recognise the need for a medication, identify what has caused/provoked the symptoms, understand which medication is appropriate and when, understand how to give that medication, and understand what the medication will achieve.

**Applying:** Recognise the relevant symptoms and signs in their child, conduct monitoring (peak flow), operate the delivery device, and interpret whether the medication is working.

**Analysing:** Differentiate asthma-related symptoms from other illnesses (e.g. common cold), appraise the severity of symptoms/signs, compare and contrast current symptoms with previous episodes and interpret course of action in light of previous advice.

**Evaluating:** Judge responsiveness to treatment, evaluate whether additional doses or other medications are required, determine if or when to obtain assistance, appraise the options for seeking medical input/advice (likely responses of health professionals, inconvenience, accessibility and cost, balancing of risks (e.g. upsetting child/exposure to night air) etc.), synthesise and describe events and actions to health professionals.

**Creating:** Formulate a course of action, construct a (preventive) management plan for the future, and assemble resources or formal/informal supports to assist.

**Challenges**

It was apparent throughout the expert panel process that there are a number of factors that make the asthma-specific demands particularly challenging; as follows.

1. The terminology of asthma is often difficult to convey to patients. The expert panel noted the difficulties experienced in explaining/translation terminology such as ‘chronic inflammatory disorder of the airways’, ‘airway hyper-responsiveness’, ‘obstruction’, or ‘persistence’ into understandable lay terms (and without affecting the original meaning). For example, panellists noted:

   *Simplify terminology: Replace “inflammation” with “inflamed airways.*

   *Airway hyper-responsiveness is a technical/medical term (and not a very good one either). It might be better to say that the muscles around the airway tend to over-react and tighten – “making the airways narrower” would be easier to understand than making the opening in the airways smaller (which opening?).*

   *Obstructed is a rather poor medical term. I think it implies a complete blockage at a single point rather than a generalized reduction in airway calibre.*

   *We have defined persistence above as referring to symptoms that occur frequently. Now we seem to be defining persistence in a different way [i.e. not resolving over a period of time]. No wonder people get confused. Can we use a simpler term than persistence?*

2. There are difficulties defining severity. Different classifications of asthma and severity can lead to confusion, even amongst medical professionals. For example, discussion of the statement “asthma severity is defined as either intermittent or persistent…” elicited the following remarks from panellists:

   *“This confuses severe asthma with unstable asthma. Asthma can be unstable but not severe, can be severe and stable, or severe and unstable.”*

   *“In my understanding, intermittent asthma is almost all virus-triggered. It is not clear whether this is a separate phenotype of asthma, or a continuity on the severity scale with persistent asthma.”*

   *“There is a fundamental confusion here. The natural history of asthma… shows at least two patterns – periodic, or continued, or as we say now, intermittent or persistent/chronic/multitrigger. The distinction has therapeutic significance.”*

3. There are limited robust measures of control available. The current measures rely on evaluation of symptoms (inherently subjective), medication usage frequency (which is dependent on both perception and training), and monitoring techniques (i.e. peak expiratory flow rate, a measure which is reliant on pre-training and understanding of normal baseline values, is particularly effort and technique dependent, and is not appropriate for all age groups).
4. Contextualising risks: although all panellists noted the importance of families being aware of the severity of asthma and the potential for fatal consequences if left untreated, it was cautioned that this message had to be carefully balanced against the risk of inducing unwarranted anxiety:

“Although the knowledge [of asthma as a cause of death] should be there it should be tempered as this can cause severe anxiety in some parents.”

5. Causes versus triggers: several panellists noted the important semantic distinction between the causes underlying the initial development of asthma, compared with the causes provoking episodes of worsened asthma (once already developed):

“I think that it is important to make a distinction between the (unknown but probably genetic and environmental) causes of someone developing asthma in the first place and the often well recognised causes that trigger symptoms. Lots of people (including many researchers in the past) have failed to recognise that these may be completely different. Hence having a cat and dog may reduce the risk of a child developing asthma, but be major triggers of asthma symptoms once they have become asthmatic.”

“…‘triggers’ is unclear. What do we mean by this – allergens, irritants, exercise. All symptoms must be triggered by something – even ‘unknown causes’ are triggers?”

6. Full asthma control is difficult to achieve:

“Perfect asthma control is rarely achieved. I think there is a conspiracy of silence about this, which may cause failed expectations, and mistrust.”

7. Difficulties giving practical advice: many panellists noted that there are limited preventive measures they are able to recommend, many of which require extensive lifestyle modification to effect properly. Many panellists were concerned that over-emphasising the role of preventive measures could result in unrealistic expectations of success, avoidance of beneficial activities, or the generation of guilt or anxiety amongst parents:

“…not sure about “avoiding triggers” this is VERY hard to do and not necessarily desirable – what if the main trigger is exercise? Kids can’t avoid getting colds and there is no way to avoid some pollens in NZ either.”

“most kids will need to be exposed to triggers (exercise, animals, grass etc.). I don’t think that parents need to feel guilty that their child with asthma is living a normal life.”

“There is a paradox of advice here. On the one hand we would like children not to have severe attacks that take them to the doctor. On the other hand we don’t want parents to hold their children back from getting medical aid when they need it in order to achieve ‘better control’ or because they feel guilty that the control is not better. On the ‘third hand’ we have limited resources to prevent virus infections…I struggle to achieve these goals in many children who are on a ‘proper medication plan’ and seem to be taking it regularly. I am wary of engendering guilt or a constant striving which results in overmedicating, on account of unreachable aims.”

8. Inadequate evidence to support claims: many panellists noted that there was a lack of clear evidence supporting a number of features of usual practice:

“[Identification of triggers:] It makes sense, but is there any convincing evidence for this?”

“There is mixed evidence about whether preventers other than leukotriene prevent exacerbations… nor has the safety of LABAs been demonstrated either I believe”.

“Is there any evidence for the efficacy of CPR in respiratory arrest due to asthma?”
KEY FINDINGS FROM THE ASTHMA EXPERT PANEL

• There are a considerable number of generic and disease-specific knowledge demands implicit in the optimal management of childhood asthma.

• Effective management draws on multiple levels of cognitive demand, not merely basic knowledge. Critical tasks require the application of that knowledge and the evaluative skills necessary to apply knowledge effectively.

• Asthma demands are complicated, even for health professionals. There is a lot of terminology, many diagnostic challenges, various classification schema, complicated risk factors, limited/subjective measures of control, and difficulties achieving outcomes and giving practical advice (balancing risks and expectations).
Health Professionals’ Assessment of Factors for Improving Children’s Understanding of Asthma

Health professionals were invited to list three factors they considered the most important for improving children’s understanding of their asthma. Responses (n = 694) to this open-ended question ranged widely, but were broadly grouped under two main categories: education topics of greatest importance, and approaches to asthma education.

**Education Topics of Greatest Importance**

Overall, the most frequently prioritised topic for asthma education was the correct use of asthma medications and devices, including inhalers, spacers and peak flow meters. This education included information about why the treatment was important, how it worked, when to use it, and training in the technical skills required for the delivery of medication. Differentiation between preventer medication and reliever medication was also highlighted, with a strongly emphasised need to provide education to parents about the importance of preventer medication in particular. Adherence to an asthma treatment plan and medication regime was also raised as a topic of central importance.

Health professionals also strongly highlighted the need to educate children and parents/caregivers in the nature of asthma as a disease, including its pathophysiology and causes. This requires children and parents/caregivers to have a good understanding of normal lung function and anatomy. There was a commonly held view that lack of appreciation of asthma as a chronic disease with potentially serious, life-threatening consequences is a major barrier to parents and caregivers taking asthma and its management seriously. As a result, many health professionals place a high priority on ensuring that children and parents understand this information.

A number of health professionals emphasised the need for children and parents/caregivers to understand what good asthma control means and what it looks like. This related to the topic of adherence to prescribed asthma medication regimes and to the correct interpretation of the signs and symptoms of worsening asthma. Development of an asthma action plan and knowledge of its correct implementation were also strongly emphasised by the health professionals.

Two of the most frequently prioritised topics for asthma education were asthma triggers and the correct identification and management of symptoms of asthma attacks. Also highlighted was the need to provide information on when to ask for help with asthma and where to seek this help.

Outside the scope of the direct management of asthma symptoms and asthma attacks was the need for information on healthy living with asthma. This included recommendations for family members to quit smoking (and information on the health risk posed by smoking to children with asthma), recommendations for exercise, and information on healthy home environments.

Finally, some health professionals emphasised the need to normalise asthma. These health professionals thought that it was important to let children and parents/caregivers know that asthma is commonplace and that a person can and should aim to have a normal lifestyle despite having asthma.

**Approaches to Asthma Education**

When discussing the best approach to asthma education, health professionals highlighted four areas of attention: 1) people who need to be involved, 2) the manner of delivery of education, 3) methods of delivery of education, and 4) the system for delivery of education.

The two most consistently reported priorities were, firstly, the involvement of parents/caregivers in the education of the child (and management of the condition) and, secondly, the alignment of the education provided to the level of understanding of both the child and the parents/caregivers.
Many health professionals highlighted the importance of keeping asthma education simple, with a significant emphasis on tailoring information and training to match the educational level and age of the child. Of note was the need to develop age-appropriate asthma education information and strategies targeting adolescents, who were viewed as having quite different needs to those of younger children and of adults with asthma. Likewise, it was considered highly important for health professionals to evaluate the parent/caregiver’s capacity for learning, and to tailor the asthma information to their educational ability.

In terms of the manner of delivery of asthma education, the health professionals frequently emphasised the need to develop a good relationship with the child and their parents/caregivers. Asthma education needs to be engaging and delivered in a friendly and approachable manner. Parents and children need to trust the health professional providing the education, and need to be encouraged to take ownership of the condition and its management. Good communication was seen as key. Many health professionals highlighted the importance of good listening skills, looking for opportunities to invite children and parents to raise questions and concerns, and seeking understanding of what influences their health behaviour around asthma management.

Physical demonstration of asthma management strategies, particularly for the use of inhalers and devices, conducted in a one-on-one environment, was most frequently seen as the best mode for delivering effective asthma education. The use of visual aids and props to help with understanding of lung anatomy, asthma pathology and the effects of medicine was also highly recommended. Furthermore, health professionals noted that the provision of asthma education needs to include processes for assessing the knowledge and skills that children and their parents/caregivers have gained (e.g. getting them to repeat back information about asthma and its management, and demonstrating correct techniques for the delivery of medication and use of devices).

Regarding the overall system for delivering asthma education, health professionals noted that the most critical element is the need to ensure that education is not a one-off experience. Many highlighted the need for repetition of information, frequency of follow-up and consistent involvement of the same health professionals over a period time.

Having sufficient time in clinical sessions to address educational needs for asthma management was also highlighted, with some health professionals indicating that this could be a problem in their clinical practice. Opportunities for cultural support in asthma education were also highlighted as necessary.

**Value of Health Literacy in Childhood Asthma Management**

Health professionals were asked to report their perceptions of the importance of health literacy as a determinant of optimal asthma management in children (Figure 12). The vast majority confirmed that health literacy is of central importance, with 86% of health professionals indicating that health literacy is either of ‘high’ or ‘extreme’ importance in asthma management. Only 1% of health professionals believed health literacy to be of ‘low’ importance.

*Figure 12: Perceived value of health literacy in optimal management of childhood asthma*
Health professionals were also asked to consider their specific behaviours and practices regarding a number of practical aspects involved in the delivery of asthma services to children. Factors were selected for inclusion on the basis of their relevance to health literacy. These factors included:

- topics of asthma education
- methods of education delivery
- strategies for checking understanding
- checking family resourcing
- perceived barriers to optimal asthma management (at the level of: the family, primary care, and secondary care services).

Each of these factors will be considered in turn in the following sub-sections.

**Topics of Asthma Education**

Figure 13 shows the likelihood of a range of topics being discussed when seeing an individual child with asthma or their family. Responses indicate that health professionals regularly cover a significant range of topics in their consultations (with 70–90% reporting ‘often’ or ‘always’ to most topics listed).

The highest proportions were in those topics relating to the pharmaceutical management of asthma, particularly when and how to take medications (94%), the use of inhalers or other monitoring devices (92%), and what to do if a child’s asthma gets worse (92%).

Other commonly reported topics were signs of uncontrolled asthma (81%), and advice on monitoring asthma symptoms (79%). There were variations by profession in the frequency of topics covered by each group of health professionals, consistent with the varying roles of each group.

**Figure 13:** “When seeing an individual child with asthma or their family, how likely are you to discuss each of the following:”

Preventive measures were less commonly discussed by health professionals, including: the identification, reduction and elimination of triggers (72%); the home environment (70%); and whether other family members have asthma (68%).
The least frequently discussed education topics related to non-pharmaceutical management techniques, including breathing techniques and exercise. These two topics were respectively discussed ‘often’ or ‘always’ by only 40% and 48% of all health professionals. Doctors were the least likely to discuss these education topics, with only 28% and 39% ‘often’ or ‘always’ discussing these topics, respectively.

Although we did not specifically enquire about the number of topics covered in the consultation, the frequency of responses to ‘often’ or ‘always’ over the majority of these 10 education topics does raise questions about the amount of information provided in a single consultation. This would have potential consequences for the ability of parents/caregivers to recall or retain the information received.

**Methods of Education Delivery**

Figure 14 shows the frequency with which health professionals use a number of different educational delivery methods or media. Verbal education through face-to-face discussion was the most common method for delivery of asthma education, with 84% of health professionals indicating they used this approach ‘often’ or ‘always’, followed by physical demonstrations (e.g. inhaler techniques) at 60%.

![Figure 14: “How often do you provide these types of information about childhood asthma:”](image)

Only 50% of health professionals reported regularly using printed materials as part of their asthma education, and fewer than a third (30%) reported regularly using pictures or photographs. Very few health professionals reported using other educational media such as: audio-visual technology (e.g. video or PowerPoint) (4%); internet-based content (e.g. websites or social media) (13%); model demonstrations (e.g. lungs or airways) (15%); or community workshops (6%).

These results have considerable implications for asthma health literacy, as verbal education techniques are merely one learning style and indicate a poor distribution of educational techniques. Furthermore, it is a combination of a range of styles (i.e. visual, kinaesthetic [tactile], and read–write) that has proven to be more effective overall than verbal techniques alone.

**Strategies to Check Understanding**

A high proportion of health professionals indicated regular use of one or more techniques to check understanding (Figure 15). The proportion using specific health-literacy techniques such as ‘teach-back’ was much smaller, however. The relatively high proportion (35%) of health professionals reporting regular use of interpreters (unspecified as to whether these are trained or family members) raises the issue of potential language barriers in clinical consultations for asthma.
Checking Family Resourcing

A significantly lower proportion of health professionals reported regularly checking the practicalities associated with whether the family would be able to implement the management strategy discussed (Figure 16). Only 55% reported checking whether the plan is manageable, 37% whether the prescription is affordable, 33% if the family have transport, 47% whether the family have access to after-hours emergency care, and 27% whether the family have or are eligible for a Community Services Card or disability benefit.

Figure 16: "How often do you use these strategies to check whether the families have the resources to manage asthma:"
Barriers to Optimal Asthma Management

Barriers at the Level of the Family

Health professionals considered family-related factors to be a frequently encountered barrier to optimal asthma control (Table 1). ‘Misperceptions regarding medications and their use’ was the leading perceived barrier, with the family’s ‘lack of knowledge about asthma’, ‘misperceptions regarding the nature or seriousness of asthma’ as a health condition, and factors in the ‘home environment’ also being reported as very frequent barriers to optimal management of childhood asthma.

Table 1: “To what extent are the following family factors barriers to optimal asthma management for children:”

<table>
<thead>
<tr>
<th>FAMILY BARRIERS</th>
<th>Rarely or Never</th>
<th>Sometimes</th>
<th>Often or Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge about asthma, its causes, and prevention</td>
<td>1%</td>
<td>26%</td>
<td>73%</td>
</tr>
<tr>
<td>Misperceptions regarding the nature or seriousness of asthma</td>
<td>3%</td>
<td>25%</td>
<td>72%</td>
</tr>
<tr>
<td>Misperceptions regarding asthma medications, and their use</td>
<td>1%</td>
<td>18%</td>
<td>80%</td>
</tr>
<tr>
<td>Complex family context (e.g. single parent, multiple carers or large family)</td>
<td>4%</td>
<td>31%</td>
<td>65%</td>
</tr>
<tr>
<td>Lack of social supports (e.g. friends &amp; community)</td>
<td>13%</td>
<td>42%</td>
<td>44%</td>
</tr>
<tr>
<td>Home environment (e.g. smoke exposure, dampness, mould, dust, etc.)</td>
<td>3%</td>
<td>26%</td>
<td>72%</td>
</tr>
<tr>
<td>School environment (e.g. policies, support, infections)</td>
<td>32%</td>
<td>46%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Barriers at the Level of Primary Care Service

In comparison to barriers at the level of the family, barriers at the level of primary care service were less often considered to be a concern by health professionals (Table 2), with the average frequency of barriers being encountered ‘often’ or ‘very often’ 61% at the level of family versus only 26% at the level of primary care. This difference suggests a clear perception amongst professionals that the basis for sub-optimal asthma management lies primarily with families, rather than with health practitioner behaviours or service constraints.

Nevertheless, the accessibility of after-hours care was considered a barrier ‘often’ or ‘very often’ by almost half of health professionals (46%). The most frequent other barriers included: the cost of prescriptions, continuity of care, the limited length of medical consultations, and the consistency of advice between health professionals.
Table 2: “To what extent are the following primary care factors barriers to optimal asthma management for children?”

<table>
<thead>
<tr>
<th>PRIMARY CARE BARRIERS</th>
<th>Rarely or Never</th>
<th>Sometimes</th>
<th>Often or Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility (transport/cost) of primary care services</td>
<td>18%</td>
<td>46%</td>
<td>36%</td>
</tr>
<tr>
<td>Accessibility (transport/cost) of after-hours services</td>
<td>13%</td>
<td>41%</td>
<td>46%</td>
</tr>
<tr>
<td>Affordability of prescriptions</td>
<td>16%</td>
<td>44%</td>
<td>40%</td>
</tr>
<tr>
<td>Continuity of care in primary care</td>
<td>25%</td>
<td>45%</td>
<td>30%</td>
</tr>
<tr>
<td>Consistency of advice between primary care professionals</td>
<td>31%</td>
<td>44%</td>
<td>26%</td>
</tr>
<tr>
<td>Length of GP consultations</td>
<td>39%</td>
<td>39%</td>
<td>23%</td>
</tr>
<tr>
<td>Access to asthma training for health professionals</td>
<td>49%</td>
<td>35%</td>
<td>16%</td>
</tr>
<tr>
<td>Access to current NZ asthma guidelines</td>
<td>65%</td>
<td>26%</td>
<td>10%</td>
</tr>
<tr>
<td>Availability of outreach nursing services</td>
<td>42%</td>
<td>42%</td>
<td>16%</td>
</tr>
<tr>
<td>Availability of kaupapa Māori services</td>
<td>50%</td>
<td>37%</td>
<td>13%</td>
</tr>
</tbody>
</table>
Barriers at the Level of Secondary Care Services

Similarly, barriers at the level of secondary care services were also less of a concern than barriers at the level of the family (Table 3). Issues such as access to specialist paediatric and respiratory services, access to spirometry, consistency of advice between primary and secondary services, and the therapeutic relationship in acute care were only considered a problem ‘often’ or ‘very often’ by 20–30% of health professionals. The most frequently reported barrier to optimal asthma management was that of consistency or quality of follow-up after an acute exacerbation of asthma, which was reported to be a problem ‘often’ or ‘very often’ by 31% of health professionals.

Table 3: “To what extent are the following secondary care factors barriers to optimal asthma management for children?”

<table>
<thead>
<tr>
<th>SECONDARY CARE BARRIERS</th>
<th>Rarely or Never</th>
<th>Sometimes</th>
<th>Often or Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent/caregiver lack of understanding about ambulance services</td>
<td>30%</td>
<td>48%</td>
<td>22%</td>
</tr>
<tr>
<td>Access to respiratory/paediatric specialists</td>
<td>34%</td>
<td>44%</td>
<td>21%</td>
</tr>
<tr>
<td>Access to spirometry services</td>
<td>46%</td>
<td>34%</td>
<td>19%</td>
</tr>
<tr>
<td>Consistency of advice between primary &amp; secondary care</td>
<td>30%</td>
<td>50%</td>
<td>20%</td>
</tr>
<tr>
<td>Developing a therapeutic relationship in an acute care setting</td>
<td>29%</td>
<td>51%</td>
<td>20%</td>
</tr>
<tr>
<td>Continuity of care throughout an admission</td>
<td>33%</td>
<td>48%</td>
<td>19%</td>
</tr>
<tr>
<td>Follow-up after an acute presentation</td>
<td>21%</td>
<td>48%</td>
<td>31%</td>
</tr>
</tbody>
</table>
KEY FINDINGS FROM THE HEALTH PROFESSIONAL SURVEY

• Health professionals recognise the importance of health literacy to the effective management of childhood asthma.

• Many note that their educative priorities are focused on promoting medication compliance, monitoring, and ensuring that whānau recognise the nature of asthma as a disease – including its causes and potential severity.

• Health professionals highlighted the need to involve whānau in the education of a child with asthma, and for information to be simple, interactive and age-appropriate.

• A number of health professionals stressed the central importance of communication style and strategies to information uptake, including: a friendly and approachable manner, and strategies to empower self-management and invite questions.

• Health professionals emphasised that for asthma education to be successful, it could not be considered a one-off. Rather, it needs to be a longitudinal process over time which builds on previous knowledge and involves a consistent relationship between the whānau and the health professional.

• Responses from health professionals indicate that they regularly discuss a significant number and range of topics in a consultation, with medication-related topics being addressed most frequently.

• Health professionals indicated that they rely most heavily on face-to-face verbal communication strategies, followed by physical demonstrations and printed hand-outs. Very few health professionals regularly use other media: pictures, audio-visual aids, models or internet technology to support their education approach.

• A significant proportion of health professionals reported using one or more techniques to check a patient’s understanding. The most commonly used technique was asking if the patient has questions.

• Fewer than half of health professionals regularly check the family’s ability/resourcing to implement the management plan discussed.

• Health professionals identified a high burden of barriers to effective asthma management within their patient’s families. Such barriers included misperceptions regarding medications, lack of knowledge regarding asthma, its causes and potential seriousness, along with the home environment.

• Health professionals identified far fewer structural barriers within primary or secondary care which may contribute to sub-optimal management.
In-depth qualitative interviews explored a range of asthma-related issues with health provider staff from five practices. Provider staff discussed where, when and how asthma education was delivered, what topics were discussed and by whom and their perceptions of the barriers to / facilitators of effective asthma health literacy for Māori tamariki. The findings are presented in key themes that emerged from the interviews:

- Asthma Health Literacy Demands (*What is taught about asthma?*)
- Asthma Education Approaches (*How is asthma taught?*)
- Workforce (*Who teaches asthma?*)
- Model of Care (*When and where is asthma taught?*)
- Cultural Responsiveness (*Cultural context and relationships*).

### Asthma Health Literacy Demands (*What is taught about asthma?*)

Most provider staff interviewed said their asthma education for patients (and parents of children with asthma) mainly focused on knowledge related to asthma medication and maintaining compliance.

“As far as dealing with children with asthma, I guess it probably is just the compliance with preventative medication, because that is definitely the goal in any poorly controlled asthmatic is just to have them on regular preventers.”

GP's noted that, along with understanding the medications, it was a parent's responsibility to identify triggers, understand how to mitigate them and recognise signs of deterioration.

“In this [Māori] patient group I feel that education is very important, educating the patients and compliance, so emphasise the preventer… Also teach them [the patients] that there are some common triggers, but different people have different triggers, and you [the patient] are the one to find that out, we don't know. You need to know your body, what are the triggers and take the medication, you can keep it under control by doing the right things, but you may get flare ups still.”

The prevalent perception amongst many GPs interviewed was that the pharmaceutical management of asthma is relatively straightforward and that effort is mostly needed to encourage compliance. Asthma plans are usually only verbally discussed in conjunction with prescribing medication, with few provider staff likely to give a written plan.

“I think asthma medications are not rocket science or anything it's very simple, but education and compliance is the most important thing, that's what I think.”

There was a general awareness that Māori have poor asthma management, but this was attributed to non-compliance to medications rather than being health literacy related. Only a few staff acknowledged that the responsibility lay with the health professional when it came to Māori patients reporting that they didn't understand about asthma.

“We should have informed our patients better…it’s just giving information, because often even if you can get that information across in a consultation, only about 40% of what you say gets retained anyway.”

Some staff mentioned the importance of teaching patients about what triggers asthma to ‘flare-up’ or worsen, in particular the environmental impact of cold, damp houses as a contributing factor to childhood asthma. They focused on explaining the importance of having warm, dry houses and advocated for improved housing conditions for their patients:

“I also look at the home environment like, you know, how damp and all that, and try to write letters to WINZ if they are in Housing New Zealand homes.”

Others spoke of educating Māori parents about smoking being most important factor causing and triggering childhood asthma.
“I really want a detailed family history; how prone to asthma they are, and I also want the smoking status of the parents. So before I talk about the asthma to parents, especially in young children, I always try to make sure that they live in a smoke free house because I feel these are the most triggering factors, you know, cigarette smoking and all that.”

**Asthma Education Approaches (How is asthma taught?)**

**Strategies to Confirm Understanding**

Many staff admitted to having difficulties confirming whether their Māori patients understand various aspects about asthma and struggled to know what level they should use to ‘pitch’ asthma education. In general, most staff said they lacked strategies for how to gauge whether their Māori patients have understood or retained the health information they give.

“It’s hard to know how basic I need to make it with some patients, what level I need to pitch my messages at.”

“[Māori patients] will say, ‘Oh usually I just come in and walk out, I come in and go out, nobody talks to me’. They probably have been spoken to by staff but they probably haven’t really understood it.”

Staff also noted that there was an acceptance that much of what they said wouldn’t be understood or retained.

“…often, even if you can get that information across in a consultation, only about 40% of what you say gets retained anyway.”

Only a few staff described approaches to checking patient understanding before providing further asthma education.

“So they need to determine where the whānau is at within their own levels of understanding … then I ask what they know about [asthma] so I can check their current level of understanding and I go from there.”

**Use of Jargon**

Many GPs used medical or technical terms when describing what they talked to their patients about.

“I say your asthma has two components, bronchospasm and the inflammation, and bronchospasm is this component and if you get recurrent bronchospasm you get inflammation and once you have got something irritable it’s going to go into spasm a lot sooner so we get the bronchospasm.”

**Reliance on Written Material**

Most staff were unsure what evidenced-based techniques or tools to use when educating whānau and instead relied on the fact that written asthma materials are probably the best tool.

“We need to be giving out more pamphlets and there probably are lots of good ones out there from the Ministry of Health, but they’re not actually that easy a thing to get hold of. It means having to go off and get them and sometimes we’ll say to students, ‘Do you want to go down to the local public health or Ministry office … and get some decent pamphlets on this?”

One GP talked about the use of and access to good-quality, user-friendly asthma resources as an effective learning tool:

“We do have some pamphlets on asthma, but I have to admit, the ones that we’ve got I don’t think are that great and so I don’t use them as much as I should. And I think just improving access to them, ‘cause there probably are really good ones out there. Yeah, it’s just making them simple and user friendly. “

A few staff suggested more effective ways they had tried recently when educating their Māori patients about chronic conditions and changing health behaviours.

“For asthma it’s all about education. We’ve been running some groups this year, mainly for diabetes, which have been run by a health psychologist to educate them and get them to actually teach each other about how they deal with their diabetes. We’ve got a group coming for smoking cessation that seems to have been very well received. Some people quite like the group education sessions. I think they make good sense and there is a specific programme, which has come out of the UK, to help people with chronic conditions deal with it in a better way.”
Workforce (Who teaches asthma?)

Some staff indicated the importance of providing a cultural context when training staff about asthma so that staff in turn had the ability to educate patients using effective methods.

“We did think of asthma training here at the marae, and we would like to have a hui here for us, that would be cool, it’s just nice to know all about [asthma].”

Lack of Training

Most provider staff reported having had only basic asthma training with little or nothing in the way of refresher training since they started practising. Staff with a good understanding of asthma usually had experienced asthma themselves or managed a child with asthma, and used this personal experience to inform their practice. Others discussed a culture of learning ‘on the job’ and the difficulty being an ‘expert in everything’.

“Only because I have asthma then I would know how to…demonstrate how to use an inhaler or spacer and things.”

“I just pick it up on the job. There’s no proper training…they don’t show us. You go to nursing school right up until the day you graduate and you become registered. Then the next day…you’re expected to know it all.”

Roles & Gaps

Most GPs reported not having time to demonstrate skills such as the use of spacers or peak flow meters, stating that they relied on either practice nurses or pharmacists to do this with patients.

“With the inhaler technique and other asthma things to explain I rely on the practice nurses to do that just to save my time.”

However, most nurses and pharmacists thought the GPs usually explained about the inhalers to the parents when they were prescribing them for patients.

“I ask if patients have any concerns about using the inhalers but none have said yes, so I assume they know how to use them after they are seen by the doctor.”

Provider staff spoke of limited opportunities to obtain up-to-date information, stating that pharmaceutical representatives were the only ones who provided training about new products, with many admitting to being unclear about current best practice for asthma.

“…we don’t really get too many updates other than medical reps coming in… but with regards to external support not so much no. I don’t know if there are asthma best practices, we’ve got the NZGG guidelines, I mean those probably haven’t changed too much in the last few years…”

“…we don’t give specific training in asthma, I think we should, but I’m just saying it takes a while, we have a huge number of services and components of service.”
Model of Care (When and where is asthma taught?)

Provider staff admitted that usually asthma information is mainly given to parents when their child presents acutely in primary or secondary care, for the first time, and is prescribed asthma medication. Generally this information is not repeated when subsequent prescriptions are issued. Instead, parents are asked if they have used the medication before, to which they reply affirmatively.

Time Constraints

GPs spoke of time constraints within a consultation as a major barrier to conveying all the necessary asthma information to parents within a 10- or 15-minute consultation and a reliance on practice nurses to fill the gaps.

“I think for a GP in a busy clinic like this, here the major barrier could be the time that we need to explain everything and also checking the inhaler techniques and other things. We need to rely quite a lot on practice nurses; however, occasionally it’s not happening.”

“We certainly make sure we do 15-minute consults, but even with that, often, you do end up being time constricted, so that does pressurise things.”

Reactive Model of Care

Staff spoke of the challenges encountered delivering best-practice asthma services under the present model of care, where most Māori with asthma are only seen when their asthma is severe and urgent treatment is needed.

“Certainly some of our patients from lower socioeconomic areas will just turn up when there is an acute problem, come in with two or three of the kids... and there's numerous things to sort out, so giving asthma plans and checking spacers often, aren't a priority ... so that is a challenge.”

Lack of Follow-up Visits

Other staff talked about the lack of follow-up visits resulting in more responsibility for parents to manage asthma on their own.

“When they don't come back, really because we have so many, you know we don't really have that luxury to be able to follow up as often as we'd like, so it is kind of putting the responsibility back on the patient, and then letting them know that if they do need us we are a phone call or a visit away kind of thing…”

Addressing Barriers to Access

Some pharmacists highlighted the current system of medication supply as an issue for some āhua, with lack of transport to the pharmacy a barrier to obtaining necessary asthma medication.

“... the other barrier is the transportation, they can't come in you know, I've got people calling me up sometimes on a Friday afternoon, “Hey I can't come in to pick up my inhalers,”… you really shouldn't leave it to a Friday afternoon to let us know, but we have them delivered free of charge which is one of the services that we provide.”

The determinants of health, such as poor housing in Māori communities, are not always apparent to health professionals, and where they are recognised as being asthma-related, providing solutions is not easily addressed.

“Sometimes I wonder about the social issues around āhua that contribute to asthma. I mean we were so surprised learning through rheumatic fever that there's such a deep level of poverty. In some ways the solutions are quite simple for what we're seeing, but of course complex in another way, but it's just like you see the deprivation in the homes, people's living conditions, the overcrowding…”
Cultural Responsiveness (Cultural context and relationships)

While there is evidence that the role of culture in health literacy is accepted, when and how to be culturally responsive in a clinical setting is not as well understood or practised amongst all health professionals.

Building Trusted Relationships

Some provider staff highlighted building a relationship with their Māori patients and wider whānau as paramount to being culturally responsive and a necessary step to consider, even prior to prescribing treatment.

“It’s actually building relationships, relationships are the first, and you need to understand the whānau, and the circumstances, you often have to bring in the rest of the whānau members, with the patient’s consent, into it, because especially with Māori you are not dealing with an individual, you are dealing with the whānau in the vast majority of cases.”

Many staff discussed the importance of establishing trust with patients, and engaging in the process of whakawhanaungatanga (building a relationship).

“We GPs… we know the whole family and we talk like friends … I would say I’ve got a number of Māori patients who just like to come and see me. I know them well, they know me well. We’ve got that sort of trust in the relationship and we can connect with them.”

Other staff recognised language as a vital part of being culturally competent with Māori and spoke of incorporating basic te reo into the conversation. For these staff, use of a familiar language contributes to the building of rapport and trust between themselves and patients.

“I think introduction in another language is so [important]… you think, ‘Oh, you speak my language.’ It just makes them feel a barrier comes down, ’cause those are the barriers that people put up in front of them.”

“…and talking a little bit of te reo helps and kei te pai.”

Māori Models of Health

Using holistic Māori models of health was seen as important when working with Māori, with the focus on hauora (well-being) rather than illness, and the need to address other urgent whānau priorities (e.g. housing, finances) before asthma management can be discussed.

“…sometimes there’s a whole lot of stuff that needs to happen before we can actually get that child seen, but making sure health professionals have a very holistic view of the world in terms of whānau health and wellbeing.”

“The homes are really cold and people don’t have money to put the heaters on let alone have a heater in the home, so they put up with it, they just think that their home is warm because they’re used to it.”

Several of the GPs and nurses acknowledged the preference Māori often express for natural herbal remedies or traditional Māori medicines (rongoā). Several provider staff noted the role that such traditional therapies may play in their patients’ wellbeing and were able to negotiate taking Western medicines alongside rongoā.

“Māori patients, their natural inclination is to go for natural stuff. If I gave them rongoā and I gave them an inhaler they would go for the rongoā first, because it’s perceived that it is better, it’s natural. It’s acknowledging that all medications have side-effects and understand their concern … and I will work with you to try and get a balance.”

Many provider staff were concerned that Māori delayed seeking expert medical help and ascribed this to cultural practices where the norm is for young parents to initially seek advice from whānau instead of taking their child to see the GP.

“If I’m a young mum and my child is sick, first of all I will ask my mother. So the grandmother will say, ‘Oh, I think your child has asthma, just try the inhalers your older children have.’ Things like this are very common among Māori families. They wait until a child is moderately ill and then they might go, ‘Oh, we should take him to the clinic.’ First of all always ask the elders in the family what we should be doing.”
**Provider Attitudes**

When talking to Māori, some health providers expressed the importance of taking a mana (prestige)-enhancing approach that builds self-esteem and a sense of achievement rather than focusing on deficits.

“The kids will tell me they have cut down smoking and I’ll go marvellous, great. Don’t put them down. A lot of these kids have been put down a lot in life. I’d rather support and enforce the good messages and the efforts they are making because often there’s a lot of peer pressure involved.”

Conversely, a few provider staff noted that they sometimes have difficulty building rapport with Māori patients, while others clearly demonstrated evidence of stereotyping and judgemental attitudes.

“I find it more difficult to establish rapport with Māori patients than I do with non-Māori.”

“The ones [Māori patients] I have problems with, I send them away. They are the ones who want the Sickness Benefit, they’re the only ones I have problems with and I don’t mind if they go because they don’t deserve the Sickness Benefit, they just want to be on it because they are lazy. I don’t believe in that Disability Allowance. All mothers have a duty to look after their children. Having to give them the asthma pump twice a day, morning and night is not a reason for the Disability Allowance. You bring forth the child, you look after the child.”

“I think most of these people [Māori]; they waste all their day watching TV. I think so, especially people on the benefit. What do they do? Morning MacDonald’s, afternoon Kentucky, evening pub, watching TV. Just a cushy life, so probably educate them from the TV.”
KEY FINDINGS FROM THE PROVIDER STAFF INTERVIEWS

- GPs acknowledged that asthma education for their patients is largely focused on medication compliance.
- Many provider staff admitted to having difficulties assessing the level of understanding of their Māori patients or eliciting questions from them.
- None of the provider staff interviewed reported having received any training in education or health literacy approaches.
- Several provider staff noted that they were unsure about current best practice for asthma or where to access relevant guidelines.
- Most provider staff recognised that building trusted relationships with parents and whānau was an essential part of working with Māori children, but some admitted that they found it difficult to establish rapport with Māori patients.
- Cultural competency was seen by many provider staff as important to building the relationship with Māori patients and whānau.
- Provider staff noted that the current model of primary health-care provides limited capacity to address chronic asthma management (e.g. time constraints, acute presentations, lack of follow-up visits).
- Provider staff noted that asthma resources are under-utilised in their current practice, and many expressed the need for resources of a better quality that are easier to access.
- Several provider staff expressed frustration that they had limited capacity to address the impacts of a number of prevalent determinants of health they identified as having an impact on childhood asthma (e.g. poor housing conditions, poverty, smoke exposure).
- Almost all provider staff highlighted difficulties providing on-going asthma support and education for children, citing limited capacity and resourcing within their daily operational requirements.
Twenty whānau (parents and children) completed the card-sort exercise (Table 4). Only 45% of whānau felt they knew ‘mostly’ or ‘completely’ about what asthma is. Almost a third stated they knew ‘nothing’ or ‘very little’ about the causes of asthma.

There appeared to be a good level of symptom awareness reported, with most whānau stating they knew ‘mostly’ or ‘completely’ about what makes their asthma better or worse (80%), the signs of asthma (85%), and how they know if their asthma is under control (85%).

Less certainty was revealed about asthma ‘attacks’, with 20% of whānau reporting they knew ‘nothing’ or ‘very little’ about how to recognise such an attack or what to do in the event of one. This may be indicative of confusion about the terminology – understanding the definition of an ‘attack’.

Self-assessed knowledge of triggers was generally weak, with only 60% reporting knowing ‘mostly’ or ‘completely’ about the common triggers of asthma and only 50% knowing how to avoid them.

There was only a moderate degree of certainty about seeking medical assistance: 65% of whānau reported knowing when to get urgent medical help and only 60% knew how to go about this.
With regard to asthma control, there was a discrepancy in self-reported understanding between concrete or tangible knowledge of asthma control (i.e. 85% recognising asthma control) versus more evaluative or abstract knowledge (i.e. 65% knowing why asthma control is beneficial). This difference between tangible and abstract knowledge (or lower- and higher-order levels of cognitive skill) was apparent across multiple categories of asthma knowledge (e.g. what asthma is, medications, peak flow monitoring, asthma plans, and engagement with health professionals).

In terms of medication, there was a striking gradient of reported knowledge across classes of inhaler, with 75% of whānau reporting knowing ‘mostly’ or ‘completely’ about relievers, compared with 55% for preventers and 10% for controllers. Fifty-five percent of whānau reported knowing ‘nothing’ or ‘very little’ about the side-effects of inhalers, and 60% knew ‘nothing’ or ‘very little’ about how the different types of inhaler work. Conversely, 75% of whānau reported knowing ‘mostly’ or ‘completely’ about spacers and how to use them.

With respect to monitoring, 85% of whānau reported knowing ‘mostly’ or ‘completely’ about how to use a peak flow meter, but significantly fewer reported knowing why to use one (65%) or how peak flow monitoring helps (35%).

Factors pertaining to chronic disease management and engagement with health professionals (i.e. higher-order cognitive skills) indicated that only 45% of whānau knew ‘mostly’ or ‘completely’ about asthma plans, 45% knew how to work with health professionals to control asthma, and 45% knew what supports to expect from school. Over a third of whānau reported knowing ‘nothing’ or ‘very little’ about asthma action plans and their use.

Table 4: Whānau Asthma Knowledge Self-Assessment (Card-Sort Exercise)

<table>
<thead>
<tr>
<th>CARD-SORT EXERCISE (N = 20)</th>
<th>Nothing or Very Little</th>
<th>Something</th>
<th>Mostly or Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 What is asthma?</td>
<td>15%</td>
<td>40%</td>
<td>45%</td>
</tr>
<tr>
<td>2 What causes asthma?</td>
<td>30%</td>
<td>15%</td>
<td>55%</td>
</tr>
<tr>
<td>3 What makes asthma better or worse?</td>
<td>5%</td>
<td>15%</td>
<td>80%</td>
</tr>
<tr>
<td>4 What are the signs of asthma?</td>
<td>5%</td>
<td>10%</td>
<td>85%</td>
</tr>
<tr>
<td>5 How do you know you or your children are having an asthma attack?</td>
<td>20%</td>
<td>10%</td>
<td>70%</td>
</tr>
<tr>
<td>6 What to do if you or your child has an asthma attack</td>
<td>20%</td>
<td>10%</td>
<td>70%</td>
</tr>
<tr>
<td>7 When to get urgent medical help</td>
<td>10%</td>
<td>25%</td>
<td>65%</td>
</tr>
<tr>
<td>8 What to do when you or your child needs urgent medical help</td>
<td>15%</td>
<td>25%</td>
<td>60%</td>
</tr>
<tr>
<td>9 How can you control asthma?</td>
<td>10%</td>
<td>15%</td>
<td>75%</td>
</tr>
<tr>
<td>10 How do you know if your asthma is under control?</td>
<td>0%</td>
<td>15%</td>
<td>85%</td>
</tr>
<tr>
<td>11 What are the benefits of having asthma under control?</td>
<td>5%</td>
<td>30%</td>
<td>65%</td>
</tr>
<tr>
<td>12 What is an asthma trigger?</td>
<td>15%</td>
<td>15%</td>
<td>70%</td>
</tr>
</tbody>
</table>
Table 4 continued…

<table>
<thead>
<tr>
<th>CARD-SORT EXERCISE (N = 20)</th>
<th>Nothing or Very Little</th>
<th>Something</th>
<th>Mostly or Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 How do you know if your asthma is under control?</td>
<td>0%</td>
<td>15%</td>
<td>85%</td>
</tr>
<tr>
<td>11 What are the benefits of having asthma under control?</td>
<td>5%</td>
<td>30%</td>
<td>65%</td>
</tr>
<tr>
<td>12 What is an asthma trigger?</td>
<td>15%</td>
<td>15%</td>
<td>70%</td>
</tr>
<tr>
<td>13 What are the common triggers of asthma?</td>
<td>15%</td>
<td>25%</td>
<td>60%</td>
</tr>
<tr>
<td>14 How do you avoid or reduce triggers?</td>
<td>15%</td>
<td>35%</td>
<td>50%</td>
</tr>
<tr>
<td>15 What do you know about how exercise and smoke affect your asthma?</td>
<td>10%</td>
<td>20%</td>
<td>70%</td>
</tr>
<tr>
<td>16 What are reliever (blue) puffers?</td>
<td>20%</td>
<td>5%</td>
<td>75%</td>
</tr>
<tr>
<td>17 What are preventer (orange/purple/red) puffers?</td>
<td>35%</td>
<td>10%</td>
<td>55%</td>
</tr>
<tr>
<td>18 What are controller (green) puffers or tablets?</td>
<td>85%</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>19 What are the side effects of asthma puffers?</td>
<td>55%</td>
<td>5%</td>
<td>40%</td>
</tr>
<tr>
<td>20 How do the different types (shape) of puffers work?</td>
<td>60%</td>
<td>15%</td>
<td>25%</td>
</tr>
<tr>
<td>21 How do you use a dry-powder puffer?</td>
<td>75%</td>
<td>5%</td>
<td>20%</td>
</tr>
<tr>
<td>22 What is a spacer and how do you use a puffer with one?</td>
<td>10%</td>
<td>15%</td>
<td>75%</td>
</tr>
<tr>
<td>23 What breathing exercises help asthma?</td>
<td>65%</td>
<td>10%</td>
<td>25%</td>
</tr>
<tr>
<td>24 What other treatments can help asthma?</td>
<td>50%</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>25 What is a peak flow meter and why use one?</td>
<td>15%</td>
<td>20%</td>
<td>65%</td>
</tr>
<tr>
<td>26 How do you use a peak flow meter?</td>
<td>5%</td>
<td>10%</td>
<td>85%</td>
</tr>
<tr>
<td>27 How does knowing your best peak flow help?</td>
<td>25%</td>
<td>40%</td>
<td>35%</td>
</tr>
<tr>
<td>28 What is an asthma action plan and how do you use them?</td>
<td>35%</td>
<td>20%</td>
<td>45%</td>
</tr>
<tr>
<td>29 How can I work with my doctor and nurse to control my asthma?</td>
<td>20%</td>
<td>35%</td>
<td>45%</td>
</tr>
<tr>
<td>30 What parents/children with asthma should expect from schools.</td>
<td>20%</td>
<td>35%</td>
<td>45%</td>
</tr>
<tr>
<td>31 How can parents/children with asthma help the school?</td>
<td>30%</td>
<td>30%</td>
<td>40%</td>
</tr>
</tbody>
</table>
KEY FINDINGS FROM THE CARD-SORT EXERCISE (Whānau Asthma Health Literacy Status)

- Self-reported confidence with asthma health literacy varied considerably amongst whānau (children ± their parent).
- Fewer than half of whānau reported a high level of confidence in understanding what asthma is.
- Most whānau reported good levels of symptom awareness, and insight into exacerbating/mitigating factors.
- Only two-thirds of whānau expressed confidence in knowing when or how to access medical help.
- Three out of four whānau expressed confidence in their understanding of reliever medications, with half understanding about preventers.
- Fewer than half of whānau expressed confidence in their understanding about asthma plans, with a third stating they knew little or nothing about them.
- A significant discrepancy was noted across all domains of asthma knowledge assessed, between the prevalence of concrete or tangible knowledge and, evaluative or abstract knowledge (i.e. low- versus high-order cognitive skill). For example, many whānau reported understanding how to complete a task (e.g. use an inhaler or peak flow meter), but far fewer reported understanding why the task is necessary or how it might help.
## Whānau Interviews

### Whānau – Ideals & Expectations

<table>
<thead>
<tr>
<th>Whānau – Experiences &amp; Capacity</th>
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</thead>
<tbody>
<tr>
<td>This section presents the themes that emerged from interviews exploring the perspectives of Māori parents and whānau (teenagers, children and extended family) managing a child with asthma:</td>
</tr>
</tbody>
</table>

- Asthma Knowledge
- Teaching Strategies
- Communication & Relationships
- Models of Care/Systems Gaps.

### Asthma Knowledge

Asthma requires a patient or parent managing asthma to have a high degree of knowledge and skills, as discussed in the previous sections. The following themes explored what parents said when asked about their experiences learning about asthma from health professionals.

#### Assumptions of Knowledge

Many parents mentioned there was an assumption from their GP that they already knew about asthma and the many components involved in managing it for their child. Parents also expressed a feeling of guilt not knowing as much as they should about asthma management and felt they should have known.

> "Like they [doctors] just think that you automatically know everything about asthma because your child has come in with asthma."

#### Lack of Information

Some parents and whānau reported having never been taught what causes asthma or triggers an asthma attack and expressed a desire to learn more about what triggers asthma and how to recognise the symptoms of asthma becoming worse.

> “…we didn’t know that she was that severe, we were giving her the reliever but that wasn’t doing anything and we didn’t know, I didn’t know that there were other things we were meant to watch, we had a bad case before we got the education. We always took it seriously but we weren’t educated about what the different stages were.”

Other parents said they had learnt from their own experience when their child was hospitalised with a severe asthma attack, while a few had done their own research using the internet.

> “No, no I didn’t get told [about triggers] until I was reading on the internet doing my own research kind of thing. So, I just picked it up …and then it’s like oh, right!”

It was apparent from the interviews that parents and whānau wanted more knowledge about a range of aspects concerning asthma management, but they felt asthma education is mainly limited to medications.

> “We always took it seriously but we weren’t really educated, we weren’t educated about what the different stages were. Like asthma was just a blue pump, when you had a wheeze you took a blue pump.”

> “I just wanted; maybe I could know more and broaden what I need to know to help my tamariki…”

A few parents discussed the importance of GPs using consultations with patients as opportunities to explain how asthma may appear mild but can quickly become life threatening.

> “When you visit your GP, I feel they don’t talk to you enough about asthma and about the severity of asthma. I tell my daughter, ‘If you can’t breathe then you die,’ I have to say it to her like that… Well the boy at that College – he died because he couldn’t breathe. Well we shouldn’t have to, not in this day and age. People should not be dying of asthma when we have got all these things that can help us prevent that from happening.”
happening… We've got to be really serious about it… If you can't breathe, you die. That's the key. That's what I say to my daughter.”

**On-going Concerns**

In general, many parents voiced concerns that their child was not given an actual diagnosis of asthma and this made it difficult for them to know what they were supposed to be managing.

“That's the thing. No one's told us, no one's actually said she's diagnosed with asthma. That's so hard for me. Even to this day I don't know for certain.”

Most parents expressed concern at giving their child asthma medication on a daily basis, particularly when their child is well. There were genuine concerns about the unwanted side-effects of steroids and an avoidance of these if possible.

“When asked the reason for not wanting to use asthma medications]…just seeing what my cousins were like before medication and then after, and watching them grow over the years and them gaining a lot of weight from being on those steroids to help with asthma.”

Some parents voiced their preferences for alternative options when treating or preventing their child's asthma.

“That's the thing that I feel that lacks in the doctors and that is they pretty much just put the drugs out there and don't give you any [alternative] option and that's where I think there is, that's the failure really.”

**Uncertainty**

When asked about what was known about the causes of asthma and its management, parents showed a high degree of uncertainty. Some parents responded positively initially that they knew 'mostly' or 'completely' about asthma (Table 4), but when asked in more depth to discuss what they knew there was a distinct lack of confidence from most parents.

“[Asthma is] something to do with his airways I think, I'm not sure.”

Most parents said they understood what makes asthma worse, but when asked for specific details they were unsure.

“[Do you know what makes asthma better or worse?] Sometimes…yes and no, no but I don’t really know.”

“I don’t know if milk does [make asthma worse] or not but I just want to avoid it, don’t give him milk…I don’t know if it’s true or not. Might be a wives' tale, I don’t know.”

“I think I know completely about what an asthma trigger is. Is it having breathing problems?”

There was uncertainty about assessing how severe asthma was for their child and using devices such as peak flow meters.

“Yes I know about peak flow meters. I've just got to think about it. What it's actually for?”

**Preventing Asthma**

A few parents discussed what they had learnt from their asthma nurse about the importance of providing a smoke-free environment for their children in order to prevent asthma attacks. They highlighted, however, that this only occurred after their child was hospitalised.

“We are more educated about the choices we make now, so but when my son came back from hospital the dog went outside and lived, there was no smoking inside the house anymore. So we've been a smoke-free whare for many years instead of smoke free whānau.”

Other parents spoke of learning by experience how to use the asthma medications to prevent asthma getting worse for their child.

“I prevent her asthma just by using that pre-ventilator [sic., the orange one, just when she's got a cold and stuff I just give it to her straightaway because I know from experience, so I do things to prevent it and I think that's sort of the control method that I use.”
Comments from some parents, however, clearly showed asthma wasn’t being managed well and on many occasions they were unable to prevent asthma attacks for their child.

“I honestly don’t think we’re managing asthma yet, because I feel like if I was managing it better, if I am on top of it, there’s things that can help but we wouldn’t have so many [asthma] turns as we do.”

No Asthma Plan

Asthma action plans have been shown to enhance asthma management and can be used as a tool to follow for everyday management as well as for worsening asthma symptoms. Very few parents knew what asthma plans are or said they had never been given one.

“The asthma action plan, actually I can’t even say I’ve seen one.”

“No I don’t have one of those asthma plans at home, so I just use Ventolin [for my son].”

A few parents discussed how their child’s asthma plan was limited to how much medication to take, but there were no instructions on recognising or preventing worsening asthma. Two parents mentioned having developed their own asthma plans out of necessity in an attempt to help them manage their child’s asthma.

“I have my own plan [for my child] but not one that’s discussed with a Dr or someone. I created my own plan, reliever medicine, Ventolin, Respigen, pretty much the same but I prefer Ventolin.”

“Yeah I enhance his [asthma plan], that sounded real bad, not so much enhance it but I …related it to him, like it is supposed to be individualised but the plan [I was given] was quite general…”

Whānau Beliefs

A widespread belief amongst Māori parents was that asthma is a normal part of growing up in their community. There was a normalisation or expectation that their children would be hospitalised with asthma, without realising that many of these hospitalisations could be prevented. When asked how the child’s asthma had been during the winter, one parent replied:

“Oh really good, awesome, he kept out of, I think he might have only gone to hospital once, and normally he’s in the hospital …once a month or something.”

A few parents discussed the belief that asthma is psychological and able to be controlled by controlling one’s feelings. They believed that asthma is a ‘mental thing’ and this had been passed on from other whānau as they were growing up. This explained why these parents declined to give asthma medication to their children but instead preferred to do breathing and physical exercises to make them strong.

“My husband believed that asthma was a mental thing, that’s what he believed growing up, and I said no it’s not until he’s seen one of the kids, he’s like what’s wrong with that child, I said she’s got asthma. So he believed it was a mental thing until I taught him that it’s not…he thought if he can control how they were feeling at that time, then that would slow their heart rate down, it would stop them from stressing out and they would be able to breathe properly.”

Many parents expressed a lack of confidence in what they knew and their ability to manage their child’s asthma effectively. These parents invalidated the knowledge they had and displayed internalised racism, ascribing poor management skills to themselves as Māori parents in general.

“I’ve written it [inhaler name] but it’s probably wrong. I’ve had it since birth and I still don’t even know how to spell it…I’m really stupid. We’re useless. We’re useless to this”.

Teaching Strategies

Parents discussed a variety of teaching strategies health professionals had used when teaching them about asthma and articulated the benefits of or their dislike for these various approaches.

Learning From Observation

Some parents said they had obtained most of their asthma knowledge from other parents and children in places like kōhanga reo (Māori-language emersion preschool) rather than learning from health professionals.
“A lot of what I know I learnt myself over the years, watching children, teaching children and learning from parents that bring kids to kōhanga reo and things like that, and yeah I suppose there wasn’t really much that I was actually taught from a medical professional.”

**Learning Preferences**

There was a clear preference for learning about asthma from observing others and from actually seeing what worsening signs of asthma look like rather than a generic statement about increasing medications when the signs get worse.

“Us Māori we don’t like reading stuff, we like visual you know.”

“Māori prefer pictures rather than lots of words. I’d like a DVD to take home and watch over and over until I knew what severe asthma looked like.”

Demonstrations by health professionals were another preferred way of learning for many parents, especially when it came to medication and spacer device use, along with demonstrations of how parents would use the inhalers and devices when they went home.

“It was during my son’s hospital stay, the nurses showed me how to do it [the pump] when they were coming in to give it. They showed me and then before I left they showed me again and then they asked me to do it.”

**Asking Questions**

Most parents said there were a lot of things they wanted to know about asthma and found it beneficial being part of the research project where they could talk freely about what they wanted to know. However, many expressed difficulty with asking their doctors to explain about asthma in a consultation visit due to perceived lack of time or not knowing how to phrase their questions. One parent shared a solution she had developed after multiple visits to hospital with her child.

“I had a list of questions the first night in Hutt hospital. My baby’s consultant photocopied those questions, and said ‘I’m going to use these in the future, I’ve never had a parent ask me questions like this’. I said ‘I’ve come from Starship Hospital where they tell me everything I need to know’, and he said ‘I’m going to use it in the future ‘cause parents don’t ask me questions like this and maybe it’s things they need to know.’”

**Easy-to-Read Plans**

Use of asthma plans written in plain language, with basic instructions, was highlighted as an effective method for understanding and following asthma treatment.

“My son’s got that peak flow in a bag [from the asthma nurse], with the asthma plan that goes with it and everything else. It’s really good when it’s easy to read and understand, yeah, well I enjoy reading it.”

**Too Much Information at Once**

It was apparent from the discussions that most parents had experienced feeling overloaded with asthma information, especially when they were given a lot of new instructions at once. Several parents and whānau admitted to having been told all about the medications, inhalers, peak flow meters and spacer devices but they struggled to remember all this information when they went home and needed to have all the information repeated until they had a thorough understanding.

“Yeah they [health professionals] have explained about the peak flow meter at the time; I suppose because I can’t get too much information all at once, I’d rather have someone go over it again later.”

**Communication & Relationships**

Establishing a trusted relationship with parents and whānau was an overwhelming priority for all parents interviewed. This was seen as the basis for being able to learn about managing their child’s asthma and becoming experts at keeping their children well.

**Lack of Confidence or Trust in Health Professionals**

Health professionals using open, effective communication with parents and whānau was seen as desirable by all parents, but many parents admitted to not having this with their GP.
“I just want to kōrero to my GP for a little bit but I just have a thing…”

Other parents expressed a lack of trust in their health professional, admitting instead they sought asthma advice from whānau members.

“I would rather listen to my father and my sister than the doctor because the doctor would tell me all different things, or not even bother…Our doctors don’t like our son.”

Conflicting Advice

There was agreement from most parents that they receive conflicting advice from doctors and this makes it difficult for them to know which advice to follow.

“It’s conflicting especially when I come here and different doctors tell me different things about the different types of relievers, so I have been told one is not good and it shouldn’t be used, then I’ve been told Ventolin is the best one to use but it is expensive, it’s not subsidised.”

It was apparent that parents were confused by conflicting advice they had received from hospital doctors and those in primary care.

“We’ve had conflicting information from different doctors, like from Wellington Hospital …actually I’ve just kind of followed the advice of Tu Kotahi Asthma Trust, which has educated me on this stuff. I’m able to draw you some lungs, what they’re kind of supposed to look like, and where they fit, and that’s through their education really.”

“It’s [challenging] going to hospital and not having doctors or nurses explain to you procedures because it seems to be different every time I go in there too. So one minute we are being told to use the bigger spacer and not to use the smaller one because it is not age appropriate and then we get told use the smaller one, you should have seen what my face looked like!”

Building Relationships

All parents interviewed agreed that developing a trusted relationship between themselves and their health professional was critical when managing asthma. Many spoke of their visits to GPs as merely renewing prescriptions, with little or no opportunity to build a relationship and have meaningful conversations.

“It’s just basically like, ‘That’s it see you later, here’s your drugs, go!’ . I don’t think that’s really helping a relationship building between you, the doctors and all their knowledge …and I’m just wanting to know, okay does my daughter have asthma, what can we do?”

Feeling Judged by Staff

A few parents spoke of being stereotyped as Māori who didn’t care about their children and feelings of ‘being judged’ by health professionals.

“I was sick of the staff judging me in hospital, thinking I was single and on the benefit…I am married and work and have my own home.”

Lack of Training

A few parents were concerned that some of the doctors they had seen did not have adequate knowledge themselves about prescribing asthma medication, and this resulted in a lack of trust in following the treatment prescribed.

“It would have been good to get a doctor that actually knew about the stuff she was prescribing to me because she prescribed these pills that she didn’t know nothing about, she’d just heard about them and was reading the book and Googling it. I was like what? I didn’t go back there.”

Not Being Listened to

A sense of frustration at not being able to communicate with doctors was discussed by several parents when it came to their child being sick with asthma.

“I’ve gotten down to the conclusion my doctors tell me nothing and we can’t tell our doctor that we know so you can’t win…I just tell him, ‘I know what he’s got, you know what he’s got, can you just check him over?’”
Most parents expressed frustration with doctors at prescribing inhalers for their child without giving an actual diagnosis of asthma or not listening to what they were trying to tell their doctor. They felt as parents they knew their child better than anyone else and that they were not being listened to.

“…not being heard too, that I know my tamariki best… my child is very fit…I go no it’s not his weight that’s causing it… they always try to tell me it’s his weight…just being listened to as I know, because they’re my tamariki, I’m with them every day, I see the signs.”

Models of Care/Systems Gaps

Parents value a meaningful relationship with health professionals who take a personal interest in their whānau and listen to a wide range of concerns. Many expressed a desire to learn about and manage asthma well for their child, but acknowledged there are a number of systemic barriers to their receiving adequate information and/or treatments. Also, other priorities such as access to doctors or financial issues often worried them and they were unable to voice these concerns or have these issues resolved.

Access to Medications

There was agreement amongst many parents that even with the subsidy the cost of the asthma medications was difficult at times, especially with more than one whānau member in the household needing prescriptions.

“I am using Respigen because me and my daughter are both asthmatics. That is an expense for two of us who are using asthma medication quite regularly so the expense is an issue.”

A few parents mentioned running out of medications and noted difficulties sourcing care or inhalers when they were away from home.

“When we’re [away from home] up in Auckland there was nowhere to get any pumps, we couldn’t ask the hospital because they can’t give it to anyone that’s not living there.”

Māori Health Services

There were some successes highlighted amongst parents who had learnt through experience or engaged with a Māori asthma nurse who educated them using a Māori approach.

“My success with asthma, well that’s been through experience really, and I’d have to say being educated by Tu Kotahi Māori Asthma Trust, that’s my success.”

No Consistent Doctor

There was a preference expressed to have a regular GP or family doctor, and concern was also expressed by parents and whānau that they often see different GPs at each visit, with asthma messages varying from GP to GP.

“Messages from the GPs vary from GP to GP, and there is nothing consistent and our whānau don’t seem to have one doctor that they see, it’s just whoever is on duty that day.”

No Follow-up Visits

Parents discussed the challenges of only seeing the GP when their child is very sick and needing urgent medical treatment. They preferred to have asthma education during a follow-up visit, when they could focus on everyday asthma management and explore preventive measures.

“When I get scripts from the doctor all he writes on it is six puffs daily until required, but he [child] hasn’t been in to see a doctor recently to get a check-up on him, nothing, no follow-up.”

Not Enough Time with GPs

Most parents and whānau wanted more time to talk with their GP, to have a meaningful discussion about factors affecting their child’s hauora (health/well-being).
“Sometimes at our doctor’s there’s only two doctors on and he just doesn’t have the time to sit there and listen and he’ll just breeze through and then bang. Then a lot of people walk away dissatisfied and you complain to the receptionist that you wanna talk to the manager and she’ll turn round and go, ‘It’s not his fault, there’s only two doctors.’”

**Holistic Models of Care**

It was clear from parents that the belief in holistic models of health and well-being was important to them. They noted this was not well recognised or incorporated into mainstream health-care systems, resulting in a lack of shared understanding between health professionals and whānau.

“That’s the thing that I feel that lacks in the doctors and that is they pretty much just put the drugs out there and don’t give you any [alternative] option and that’s where I think there is, that’s the failure really, the way the system is set up. They just talk about the drugs.”

**Preferred Place to Learn**

A few parents talked about the difficulty they had understanding all the instructions the doctors gave them in hospital because they were so worried their child was going to die at the time that they couldn’t remember all the information they were given when they went home. Some parents preferred learning about health and well-being in their home or community, such as at the school with their child.

“What’s the best way for you to learn about asthma?] Getting taught about asthma at home and getting a nurse in at school also.”

**Asthma Health Literacy Needed in Schools**

Continuity of asthma management when children are at school was a concern for all parents, many of whom tried to educate teachers themselves about the many aspects of their child’s asthma. Children were kept home frequently due to their asthma, with parents stating they didn't have confidence that school staff managed their child’s asthma properly.

“Well I wish we could expect more [from schools], I really do wish it was more ’cause I take his pumps to school and I have to take it in to the office, but he’s never ever used them at the office, he still comes home with his asthma. Even though he said that he’s had his asthma they don’t give him his pumps.”
KEY FINDINGS FROM THE WHĀNAU INTERVIEWS

- Many whānau felt that they did not get told enough about their child’s asthma to manage it effectively. Parents noted lack of information on the stages of disease, indicators of severity, potential seriousness of the condition, common triggers, and the role of the various medications. Several whānau said that they had never been provided with a formal asthma plan.

- Several whānau voiced concerns that their child had never been given a specific diagnosis of asthma and this made it difficult for them to know what they were managing.

- Many whānau expressed difficulty with asking doctors to explain about asthma in a consultation visit due to perceived lack of time or not knowing how to articulate their questions.

- Several whānau identified that they had unresolved issues or on-going concerns that had not been addressed, particularly concerns regarding medication side-effects. Other parents expressed a sense of ‘not being listened to’ by their health professional or not being recognised for the insights they could offer into their child’s condition.

- Whānau expressed a desire for GPs not to assume what they knew about asthma but to use a step-by-step approach when educating about all aspects of asthma management.

- Whānau articulated wanting to work in partnership with staff to develop individualised, clearly written asthma action plans that they were confident to implement with their children.

- Demonstrations by health professionals and the use of visual resources were commonly preferred ways of learning, especially when it came to medication and spacer device use.

- Establishing a trusted relationship with health professionals was an overwhelming priority for all whānau interviewed. This was seen as the basis for being able to learn about managing their child’s asthma and becoming experts at keeping them well.

- There was a preference to have a regular GP or family doctor, and concern was expressed by whānau that they often see different GPs at each visit, with asthma messages varying between different health professionals.

- Many whānau wanted to discuss holistic options of preventive care and for maintaining their child’s well-being – in addition to pharmaceutical approaches. Several expressed a preference for having asthma education during a follow-up visit in their homes or in the community, or with a Māori asthma nurse.
Resources

Resource Review

Whānau – Ideals & Expectations

Written resources are used by primary care providers to inform patients and whānau of a range of different aspects of asthma prevention and management, including using devices. These resources represent a critical health literacy demand placed on patients and whānau.

A total of 26 resources were reviewed. Fourteen resources were collected during visits to primary care settings or from the researchers. Resources were collected from clinic reception areas, treatment areas or pharmacies. We also accessed other resources from New Zealand websites. Three of these resources were in fact New Zealand websites about asthma. We accessed online resources to replicate what whānau might do if they were searching for information about asthma.

Resources fell into three groups:

- seven resources with general information about asthma (for both adults and children)
- 10 resources with specific information about aspects of asthma; for example, asthma and smoking; asthma and physical activity; asthma and healthy homes (aimed at adults with asthma or adult caregivers)
- nine resources about management plans, symptom diaries, control tests (aimed at both adults and children).
This review is not an exhaustive analysis of all asthma resources because this is outside the scope of this project. Instead, this section contains an overview of the resources collected from a number of general practices, online sources and those supplied by the Asthma Foundation.

**Evaluation Criteria**

The following evaluation criteria were used to review the selected resources: 51

- clear or implied purpose
- specified or implied audience
- resource type
- access point
- vocabulary
- language and text features (e.g. layout, white space as well as use of visuals, which helps to create contextual meaning)
- inclusion of Māori concepts and values.

**Description**

All of the resources were developed in New Zealand or modified from overseas content to be used in New Zealand. One resource was developed by a pharmaceutical company. The only specific Māori resource was written by a Māori asthma educator as part of her role with the Bay of Plenty Asthma Society.

The majority of the resources were published from 2003 to 2013, with 17 resources developed from 2010 to 2013. The four oldest resources are available online and yet look quite dated, especially in relation to the visuals used. Three resources did not supply dates. The clinical content of these resources was not part of this review process.

Only two resources contained stories suitable for children with asthma and their whānau. One resource was about medication and another resource was about using a peak flow meter. Some resources contained both information and instructions. None of the resources contained a clear statement that there were these two different types of information, nor signalled when you were moving between information types. Readers use different reading strategies when reading different types of textual information, and it is useful to signal to the reader when the text changes so the reader can change strategies.

**Purpose**

Three resources did not have an explicit or implied purpose. Having a clear stated purpose helps the reader to understand why they are reading the document. The three resources that did not have a stated purpose required reading and re-reading before the reader understood what they were meant to do.

**Audience**

One resource did not have a stated or implied audience. However, some resources (and websites) had multiple audiences and this showed in the clarity (or lack thereof) of the messages. It was more apparent when the audiences were quite divergent (e.g. health professionals, researchers, educators and people with respiratory disease).

**Vocabulary**

While a few resources used clear vocabulary and explained technical terms, most resources would benefit from the use of ordinary everyday language and explanations of technical terms. These terms were often used with the assumption that the reader would know and understand them (e.g. croup, whooping cough, mucus, viral respiratory tract infection, flu, drip dry, upright, seal, electrostatic, mild, moderate, sudden onset and crucial).
**Visuals**

Some resources made good use of visuals to reinforce key messages or instead of text. A number of resources used traffic-light colours to indicate various disease stages, particularly in relation to management and emergency plans. This makes it clear to the reader, as these sorts of visual cues are well understood by most groups in New Zealand.

However, more than half of the resources had visuals that were inadequate for the following reasons:

- too small to be useful
- without a contextual reference (e.g. where the lungs are in your body)
- dated (nurse in a white uniform with a cap)
- included without explanations of how to read them (e.g. tables, charts and graphs that require good reading skills)
- incongruous with the text – a picture of a doctor smiling when the resource is about an emergency plan
- too small in resources where there was space to have much bigger visuals
- not reflective of the diverse population groups in New Zealand who have asthma.

**Inclusion of Māori Concepts and Values**

Only one resource, written by a Māori asthma educator, included Māori concepts and values. Two other resources included some reference to Māori concepts and values, but these were not overt. One of the resources reviewed stated it is available in te reo Māori, but this resource is not available for download. Considering the high proportion of Māori in the population with asthma it was surprising that more resources have not been developed specifically for Māori.

**Level of Health Literacy Required**

Generally these resources required a moderately high level of knowledge and skills relating to asthma. Partly this may be because the majority of the resources were about special aspects of asthma and there was a presumption that people already had a baseline knowledge.

**Health Professionals’ Perspectives**

Three health professionals from different primary health organisations referred to using asthma resources with patients, but none were able to locate the actual resources at the interview. One GP said he would use written resources more often but they were unavailable in his practice and he was unsure where to order them from. Health professionals did not identify how they selected resources to fit patient/whānau needs, nor did they identify how they used resources with patients/whānau (e.g. handed them out at end of consultation, went through them with patient/whānau, and so on).

**Whānau Perspectives**

No participants (whānau or children) identified any written resources they received from health professionals. A few parents said that hands-on resources (such as models of breathing tubes and lungs) had helped them understand the physiology of asthma, including what happened in the airways during an asthma attack, what normal air passages look like, and the size and position of the lungs. There was a clear preference for visual or hands-on resources that enabled them to understand what was happening to the lungs during an asthma attack and how the lungs and airways looked when asthma was under control. Whānau also identified other information they wanted to know to help them assist their children with asthma. This included pictorial asthma plans, electronic and video resources, as well as asthma resources suitable for use in schools.
Use of Resources

This review shows that a number of freely available asthma resources in New Zealand could be improved. However, resources should never stand alone: they need to be part of a conversation between a health professional and the patient/whānau. A good conversation between a health professional and patients/whānau can overcome the problems of a poorly written resource. Conversely, a poor conversation with a health professional using a good resource may cause patients/whānau not to read the resource. This review did not include observation of health professionals engaging with patients/whānau and using any written or visual resources.

KEY FINDINGS FROM THE ASTHMA RESOURCE REVIEW

• Most resources required a moderately high level of knowledge and skills about asthma.
• Several resources contained specific jargon and terminology that were not explained within the resource.
• More than half of the resources reviewed had visuals that were inadequate for the intended purpose.
• Overall the resources did not reflect the diverse population groups in New Zealand who have asthma. Only one resource was based around Māori concepts and values. Two other resources included some reference to Māori concepts and values, but these were not overt.
• No audio-visual or New Zealand-specific internet resources were identified.
• Whānau showed a clear preference for visual or hands-on resources that enabled them to understand what was happening to the lungs during an asthma attack and how the lungs and airways looked when asthma was under control.
• Resources should never stand alone: they need to be part of a conversation between a health professional and patient/whānau. No training or usage guides for health professionals were available to accompany any of the resources reviewed to indicate how they were intended to be used.
Health literacy is a social determinant of health that offers a powerful opportunity to reduce inequities in health. This study has demonstrated that managing asthma is a complex, multi-faceted process, which places a significant number of dynamic health literacy demands on whānau to effectively manage a child’s asthma.

**Communication**

The responsibility for health literacy lies primarily with health professionals: to consider how we might be contributing to knowledge deficits, and to develop evidence-based strategies to overcome these. This responsibility is a key factor in lifting health literacy levels, as it is the health professionals’ skills and expectations that drive health literacy levels in their patients. Good asthma education requires health professionals to have excellent communication, active listening skills, and the capacity to invest adequate time into interacting with tamariki and their families. Repetition of education by the same health professional on more than one occasion is strongly recommended. Questions or concerns about asthma should be actively sought. Asthma education should also be associated with explicit strategies to assess the child’s/family’s understanding of key asthma information, along with observation of their ability to correctly use asthma devices and to follow an asthma action plan.

Building asthma health literacy requires improved asthma knowledge and the ability to put this new knowledge into action. This will enable parents and tamariki to gain greater self-control over their health and the decisions they need to make. Similarly, building asthma literacy requires more than the provision of clear information: it also involves purposefully developing relationships and having knowledge of tamariki, whānau and their communities.

This building process draws on principles of adult education and learning and requires health professionals to act as adult educators. In doing so, they draw on a patient’s prior knowledge and experience in order to strengthen the patient’s understanding of health. Starting with what the patient knows about their own condition opens the door to increased interaction, participation and critical thinking. In order to build asthma literacy, whānau need to understand what asthma is and how it affects their child, and the benefits of following the asthma treatment. Health professionals would do well to shift the focus from medication compliance to incrementally increasing a parent’s/child’s understanding of asthma, listening to their concerns, and supporting them to recognise signs and respond to the changing nature of chronic asthma.

Reducing any unnecessary asthma literacy demands may involve providing limited and prioritised information to parents and tamariki. Initially the emphasis should be solely on ‘to do’ tasks (i.e. taking inhalers, using a spacer), then on providing increased (but clear) information to patients on recognising worsening asthma and implementing an individualised action plan. All the while health professionals need to be aware of providing more opportunities over time in which to build a parent’s and child’s knowledge and skills.

While most health professionals understand the importance of the concept of health literacy for optimal asthma management, many recognised the difficulties in conveying health information to patients in an understandable manner. No health professionals we interviewed reported any formal training in education or health literacy techniques.

**Self-Appraisal of Knowledge**

Despite most health professionals using a range of informal techniques to gauge understanding, many admit they find it particularly challenging to assess whether the parent or child has fully grasped key asthma messages. Our data indicate that health professionals assume that if parents say they understand and do not ask questions, they have a good level of understanding. The responsibility then falls on the parent/patient to seek further education – which is dependent on patients knowing what they need and finding out what is available.

‘We don’t know what we don’t know’: it is a well reported phenomenon in psychological literature that people overestimate their own abilities. Also, it has been observed that people with limited skills tend to lack the ability to recognise these limitations, frequently leading to unfounded overconfidence –
the so-called Dunning-Kruger effect. This effect manifests itself as individuals with lower skill levels mistakenly rating their ability much higher than is accurate, while individuals with higher skill levels rate their ability lower than is accurate. The difficulty is that the cognitive abilities we use to assess our level of understanding something are the same abilities we have to understand the thing itself. Improving a person’s skill increases their metacognitive ability, and in so doing helps them better recognise their limitations; that is, the more you know, the more you realise you don’t know.

This concept is of profound importance to health literacy. In this study we have observed strong evidence of the Dunning-Kruger effect amongst both the patients and the health professionals we interviewed. Both patients and health professionals rated their own competencies higher than the respective evidence suggested. This phenomenon has implications within clinical consultations and asthma educational settings, as clinicians report relying heavily on the patient’s own assessment of their understanding, self-reported confidence in managing, and ability to generate questions as indicators of level of understanding.

The implication is that in many cases these mechanisms are likely to be unreliable forms of assessing understanding and lead to incorrect conclusions (e.g. parents’ initial rating of their asthma management knowledge was relatively high, but on further inquiry this rating was more accurately lowered). This indicates the need for non-threatening, supportive ways by which a clinician or patient can objectively gauge understanding. Hence, there is a need for more formalised health literacy training tools along with patient self-assessment resources. Further research is needed to develop, implement and evaluate the effectiveness of such tools to ensure they not only incorporate robust health literacy approaches but are also appropriate and acceptable to the communities they are intended for.

**Information Resources**

It is important that information and training is provided in a friendly and engaging manner. Educational materials and one-on-one training should be presented at a level the child and their family understand, taking into account the child’s age, learning capacity and level of existing knowledge, with an emphasis on keeping information as simple as possible and building on existing skills.

The asthma resources review shows that a number of asthma resources in New Zealand could be improved. Resources, however, do not stand alone; instead they need to be part of a quality conversation between a health professional and the patient/whānau. A good conversation between a health professional and a patient and whānau can overcome the problems of a poorly written resource. Conversely, a poor conversation, using a good resource may result in patients/whānau not reading or understanding the resource.

**Context**

Our data clearly indicate that the context – when, where, by whom and how asthma education is delivered – plays an important part in its effectiveness. The best time to educate whānau about asthma is proactively – when the child is well and parents/caregivers are more receptive to learning. However, the current health system is configured for health professionals to primarily see patients on a reactive basis, when asthma is out of control and needs acute management. The advice and education given under those circumstances is different from that which would be given to support long-term condition management, and the whānau’s ability to understand or retain that information is often compromised (e.g. if the parent is anxious and care is needed during the night, or with an on-call health professional who is not familiar with the child). An effective approach, a suitable environment and appropriate time all contribute to how well parents and children learn to manage asthma effectively.

Optimal disease management cannot be accomplished solely by the input of a single practitioner. Modern approaches to the delivery of health care emphasise collaborative relationships between families and several health-care professionals and providers, along with an increased expectation for self-management. Families whose children have ongoing health conditions have new roles and responsibilities and must carry out elaborate health-care regimens, make on-the-spot medical decisions, and problem-solve medical challenges while balancing multiple other demands. Effective collaboration, both within a multidisciplinary team of health care professionals and with the parent, is the cornerstone of successful outcomes.
Health System Factors and Patient Activation

Increasingly, patient self-management and activation play important roles in the management of chronic conditions and are closely tied to health literacy. People who are “activated” recognize that they have an important role in self-managing their condition and have the skills and confidence to do so, and those who are more activated experience better health outcomes. Research has shown that activated patients are more satisfied with medical encounters overall, are more likely to undertake self-management, and are more likely to be satisfied with and adhere to treatment protocols. Also, patients who are more involved in consultations are more likely to have treatment plans that are structured around their own lifestyles and beliefs.

Patient activation is a “modifiable characteristic” and evidence shows that levels of activation can be strengthened among even those who are “initially less confident, less motivated or have low levels of health literacy.” Furthermore, activation may help to compensate for numeracy and literacy skill deficits, or lower levels of health literacy. If activation can improve motivation and help patients to better understand the consequences of health-care choices, they are more likely to understand and use relevant health information.

Alongside measures to improve patient activation and self-management (i.e. interventions with patients and implementing changes in patient–practitioner interactions), changes need to be made within the health system overall to better meet the needs of people with chronic conditions.

Our findings indicate that many whānau are confused by the asthma demands facing them and find their engagement with the health system frustrating due to its lack of provision of longitudinal care (i.e. a chronic disease management approach). Both whānau and health professionals identified a number of barriers to effective asthma education and health literacy, many of which were systemic.

Clear evidence was obtained from both whānau and health professionals of the model of asthma care being focused almost exclusively on acute episodic care (i.e. presentations to primary care were predominantly for acute exacerbations). Whānau reported that little proactive follow-up was occurring (e.g. when the child was well, or following ED presentations or hospitalisations) for the purposes of ongoing education and chronic illness management. It was clear that this model of care caused confusion for whānau regarding the ‘on-going’ nature of the illness, and the lack of contact during periods of wellness meant that whānau were more often given advice pertaining to acute management rather than general preventive advice. Also, whānau commented that the majority of the health-care contacts had been in relation to acute (often severe) events, at which time they were not in the correct frame of mind to retain information of a preventive/chronic care nature. Most health professionals interviewed also noted that they had inadequate capacity within their routine care schedules to provide in-depth or on-going asthma education support.

To better support health literacy, health system changes need to “involve a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive.” The World Health Organization’s Innovative Care for Chronic Conditions (ICCC) provides an important internationally applicable framework in a move towards better service provision for people with chronic conditions.

The ICCC was formulated through a review of the Chronic Care Model, which incorporates changes in health care organisation, improved and accessible community resources, self-management support, changes in delivery system design, and an improved clinical information system. The ICCC argues that patients should be informed, motivated and prepared, and have access to the necessary medications and medical equipment. It places a strong emphasis on continuity and coordination of services and stresses the importance of communities supporting organised health-care efforts around the management of chronic conditions. Furthermore, the framework recognises that chronic care delivery has limitations at three distinct operational levels: patient interaction problems, problems with health care organisations and their links to the community, and policy problems. Figure 17 illustrates key deficits that are evident...
in current health-care systems, for which the ICCC framework was designed. Our findings demonstrate remarkable concordance with many of the issues identified in this framework.

Figure 17: ICCC Framework – Current Systems Are Not Designed for Chronic Problems

<table>
<thead>
<tr>
<th>Patient Interaction Problems (Micro Level):</th>
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<tbody>
<tr>
<td>1. Failure to Empower Patients</td>
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<td>2. Failure to Value Patient Interactions</td>
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<tr>
<th>Problems with the Health-Care Organisation &amp; Links to the Community (Meso Level):</th>
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<tbody>
<tr>
<td>1. Failure to Organise Care for Chronic Conditions</td>
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<tr>
<td>2. Health-Care Workers Lack Tools and Expertise</td>
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<td>3. Practice Is Not Informed by Scientific Evidence</td>
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<td>4. Failure to Address Prevention</td>
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<td>5. Information Systems Not in Place</td>
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<td>6. Failure to Connect with Community Resources</td>
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<tr>
<th>Policy Problems (Macro Level):</th>
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</thead>
<tbody>
<tr>
<td>1. Legislative Framework Is Lacking</td>
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<tr>
<td>2. Health Policies and Plans Are Outmoded</td>
</tr>
<tr>
<td>3. Governments Are Not Investing Wisely</td>
</tr>
<tr>
<td>4. Financing Systems Are Fragmented</td>
</tr>
<tr>
<td>5. Provider Incentives Are Misaligned</td>
</tr>
<tr>
<td>6. Standards and Monitoring Are Insufficient</td>
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<tr>
<td>7. Continuing Education Is Lacking</td>
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<tr>
<td>8. Intersectoral Links Are Overlooked</td>
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**Summary**

This study demonstrates that the health literacy demands of managing a child with asthma are complex and multi-faceted.

It was apparent that whānau were making significant efforts to effectively manage their child’s asthma with the knowledge and skills they had, though most were under-confident in their own abilities and recognised the need for more understandable asthma information. Whānau expressed widespread frustration at the lack of proactive holistic care, and failure of the health system to respond to their needs.

Similarly, there was widespread recognition amongst health professionals of the importance of health literacy to optimal asthma management. It was evident most were making genuine efforts to recognise the needs of their patients and deliver information in understandable ways. However, it was also clear that they faced a number of challenges in delivering quality asthma care – due predominantly to lack of adequate capacity, resources and specific health literacy training.

In determining our recommendations we have adopted a systems approach to health literacy, to avoid the deficit notion of poor health literacy whereby it is considered the responsibility of the patient/whānau. All whānau have their own levels of knowledge, skill and internal resources to manage a chronic illness; however, it is our assertion that the health system must accommodate whānau equitably. We conclude that the predominant barriers to optimal health literacy for Māori children with asthma are structural, endemic to the acute care model of health delivery that currently predominates.
We therefore advocate a systematic health literacy-based approach to asthma education for Māori children.

In the recommendations section that follows, we present our findings within the four emergent themes arising from the thematic analysis:

1. Mātauranga (Knowledge)
2. Whakaakoako (Teaching Strategies)
3. Whakawhanake (Workforce Development)
4. Te Anga (Model of Care).

Within each theme we present recommendations according to a three-level approach: macro (health systems), meso (health organisations) and micro (health professionals). Each of these levels interacts with and influences the other two. When these levels work effectively within themselves, and successfully function in relation to each other, health care is both efficient and effective and patients experience improved health outcomes.
PART 5: RECOMMENDATIONS
PART 5: RECOMMENDATIONS

Mātauranga (Knowledge):
Delivering Understandable Best-Practice Asthma Advice for Māori Children

Health System (Macro Level)
The health system needs to recognise the burden of asthma facing New Zealand society, and Māori children in particular. It must take action to promote widespread public awareness of asthma, its causes, and the potential seriousness of the condition. It is vital that updated New Zealand-specific guidelines for the management of childhood asthma be developed that cater for our unique population, specific health environment and latest therapeutic options in order to ensure the provision of consistent, up-to-date, evidence-based best-practice information.

Recommendations

• Promote enhanced public awareness of asthma, its potential seriousness and preventive measures.
• Work in partnership with the education sector to integrate fundamental asthma health knowledge into school curricula.
• Update New Zealand-specific best-practice management guidelines for paediatric asthma.
• Develop step-wise learning objectives and a curriculum for asthma management.
• Fund research that provides evidence for effective asthma interventions that activate and empower whānau to support children with asthma.

Health Organisations (Meso Level)
The maintenance of clinical skills is an on-going task. Health organisations need to assume responsibility for the maintenance of best-practice standards within their organisation and for the provision of in-service training of their staff with respect to asthma management. Asthma is a chronic disease, and asthma education is a longitudinal, step-wise process. Information systems are important to monitor asthma care, alongside the provision of asthma education, to ensure elements are not accidentally omitted and relevant items are reinforced periodically.

Recommendations

• Invest in regular in-service training for staff on asthma best practice.
• Utilise GP patient management systems to provide longitudinal asthma education monitoring.
• Develop asthma training packages for patients, whānau and communities.
• Nominate a staff member to the role of ‘asthma champion’ with responsibility for leading uptake of best-practice guidelines, resource implementation and quality assurance monitoring.
• Include the populations served in the design, implementation and evaluation of health information and services.
Health Professionals (Micro Level)

Health professionals need to be able to provide up-to-date best-practice asthma care for Māori children which takes account of the: age of the child; level of severity or treatment step; existing knowledge; learning style; and cultural preferences of the whānau. All children with asthma should have clear, individualised, asthma management plans (developed in partnership with the whānau) and be able to effectively implement them. Asthma education needs to focus more broadly than disease-specific knowledge and medication compliance to incorporate holistic objectives, including health promotion, self-management and disease prevention.

Recommendations

- Maintain a high level of competency in current best practice for the management of childhood asthma.
- Ensure all children have access to individualised, understandable asthma action plans.
- Follow a step-wise education plan when providing asthma support to Māori patients.
- Provide updated electronic access to asthma plans for whānau, community health workers and schools.
- Routinely utilise specialist (medical and/or nursing) respiratory and paediatric expertise to effectively manage those whānau with complex health-care needs.

Whakaakoako (Teaching Strategies):
Using Effective Strategies to Communicate about Asthma with Māori Children

Health System (Macro Level)

The health system needs to recognise and promote the importance of health literacy and chronic disease management competencies for all health professionals and other health-care workers involved in asthma management. Health professional bodies and academic training institutions need to ensure adequate provision of training in these areas and provide monitoring in the attainment of these skills. The health system must also promote the integration of cultural competency, cross-cultural communication and holistic Māori models of health into all levels of the health sector to ensure the health workforce are equipped to engage in meaningful collaborative partnerships with Māori patients.

Recommendations

- Influence medical, nursing and pharmacy schools and other health training programmes to teach health literacy and chronic care management to students.
- Establish and monitor competencies for all health professionals in health literacy education and chronic disease management.
- Set an expectation within health policies and strategies that all health services will deliver high-quality care that focuses on meeting the health needs and aspirations of Māori children with asthma.
**Health Organisations (Meso Level)**

Health organisations need to work collaboratively with the populations they serve to identify and develop high-quality resources for children with asthma and to incorporate these into their educational strategies (particularly interactive and audio-visual resources, along with resources designed specifically to address the needs of Māori children). There is a need for education support tools for asthma to monitor the longitudinal provision of asthma care for Māori children and their whānau. Innovative, flexible and community-based asthma educational approaches need to be adopted to better meet the needs of Māori whānau.

**Recommendations**

- Work collaboratively with children with asthma to develop high-quality asthma resources for a range of ages and levels of asthma knowledge – particularly interactive and/or audio-visual resources, and resources specifically for Māori children.
- Develop longitudinal asthma education support and monitoring tools for patients/whānau.
- Develop community-based, health literacy asthma support and education sessions that are culturally appropriate for Māori children and whānau.

**Health Professionals (Micro Level)**

Teaching strategies employed by health professionals need to engage the patient and their whānau according to the specific needs and learning preferences of the family. They need to empower and activate patients to be able to take an active role in their own health care, and provide them with the tools to do this. This involves a requirement for specific training in health literacy-based education techniques, chronic disease management education strategies and cultural responsiveness. High-quality resources utilising a range of media need to be available which can support health professional-led engagements, and reinforce key messages for all ages and levels of understanding.

**Recommendations**

- Ensure all consultations are seen as opportunities to build health literacy, promote patient activation and support asthma self-management.
- Undertake specific training in the use of health literacy-based education techniques.
- Regularly incorporate a variety of learning media (e.g. interactive/tactile/audio-visual asthma resources) to support asthma education.
- Continue to develop cultural competency skills for engaging with Māori children and whānau.

**Whakawhanake (Workforce Development):**

*Building Relationships and Working Together to Support Māori Children with Asthma*

**Health System (Macro Level)**

In order to meet the on-going needs of Māori children with asthma (and other chronic diseases) the health system must develop a range of health-care personnel equipped to meet the specific challenges of providing chronic disease management. This must include coordinated development of inter-professional and team-care strategies that clarify roles and expand scopes of practice to provide integrated support for chronic disease management. Such inter-professional approaches need to include recognition of the roles that asthma educators, pharmacists, non-professional health-care workers, community organisation staff and trained volunteers can have in supporting the provision of holistic integrated asthma care.
Recommendations

• Explore models of integrated care to promote closer working relationships between health professionals, and enhanced inter-professional learning opportunities.

• Improve role delineation for health professional groups in the chronic disease management of asthma in support of a multidisciplinary support approach.

• Formalise and expand scopes of practice for other health-worker roles (such as asthma educators, pharmacists and community health workers) to support the provision of holistic integrated asthma care.

Health Organisations (Meso Level)

Effective asthma care requires a team approach. Health organisations need to develop and adopt policies and procedures that encourage better interdisciplinary harmonisation. This also involves a need for improved links with other providers within and beyond the health sector to address the dynamic and holistic well-being of Māori children with asthma. Health organisations must also mandate the inclusion of cultural competency across the organisation to ensure all staff understand and practise effective ways of engaging with Māori in clinical settings.

Recommendations

• Provide policies and procedures for cross-disciplinary harmonisation of asthma management and education.

• Develop collaborations and provider networks (e.g. within and between DHBs, PHOs, Māori providers, NGOs and other community agencies) to support implementation of best practice for asthma and chronic care management approaches.

• Mandate the inclusion of cultural competency across the organisation to ensure all staff understand effective ways of engaging with Māori in clinical settings.

Health Professionals (Micro Level)

Effective asthma management requires the establishment of long-term trusted relationships with patients in order to build a shared understanding of values, priorities and management strategies. No individual health professional has sufficient capacity or capability to be the sole provider of asthma management support. Health professionals need to establish collaborative relationships with their professional colleagues and community partner organisations to develop a shared understanding of the responsibilities for asthma education in order to ensure the education is consistent, timely and comprehensive.

Recommendations

• Maintain continuous high-quality relationships to build long-term trust relationships with patients.

• Routinely explore the manageability of asthma management plans and utilise relevant support services to address identified barriers.

• Develop collaborative partnerships with Māori health providers, Whānau Ora providers and other community-based organisations in support of asthma care for Māori children.
Te Anga (Model of Care):

*Health Care Services That Meet the Health Needs of Māori*

**Health System (Macro Level)**

Critically, the health system must recognise that the current system based around reactive, episodic care is failing Māori children with asthma, and is being manifested in significant inequalities in asthma health outcomes. The health system urgently needs to implement a chronic care management model to provide proactive, longitudinal, patient/whānau-centred, culturally responsive care to Māori children with asthma within a multidisciplinary team environment. The health system must also ensure services for asthma are integrated to provide shared information across settings, providers and time – minimising fragmentation, service delivery gaps and patient frustration. Integration must also include extending policies that support patient-centred health care, prioritise health promotion, engender patient activation and encourage self-management.

**Recommendations**

- Implement a systematic chronic care management model for asthma care to provide long-term, proactive, whānau-centred multidisciplinary support.
- Develop and support shared information platforms allowing integration of asthma support and monitoring between providers.
- Align provider incentives so that proactive chronic disease management efforts are rewarded.
- Allow flexibility within Care Plus eligibility criteria to include asthma as a single qualifying condition.
- Fund a free annual asthma review in primary care.

**Health Organisations (Meso Level)**

Health Organisations need to adopt a proactive chronic care management approach to all aspects of asthma support within organisational policies and procedures. Health literacy policies and procedures also need to be integrated into the organisational culture so that every asthma interaction aligns with effective learning outcomes. These organisations need to contribute to generating evidence that informs community initiatives that activate whānau and build asthma self-management capabilities, and incorporate mechanisms to support holistic well-being for Māori children with asthma.

**Recommendations**

- Develop and implement health literacy policies and procedures for staff.
- Adopt a proactive chronic care management approach to all aspects of asthma support within organisational policies and procedures.
- Incorporate a philosophy of culturally competent holistic care into organisational policies and individual consultations with Māori.
- Contribute to the generation of evidence-informing initiatives to activate whānau and build asthma self-management capabilities.
**Health Professionals (Micro Level)**

Māori children with asthma face significant barriers to effective asthma management. Although many of these barriers have their origins in inequalities of the determinants of health, it is imperative that health professionals recognise the contribution of barriers within health care that contribute to sub-optimal outcomes. Health professionals need to ensure that all their patients are receiving eligible supports or benefits, and that accessibility or affordability are not preventing optimal health outcomes.

**Recommendations**

- Routinely incorporate chronic care management approaches into asthma consultations, including using proactive strategies to provide preventive advice when patients are well.
- Ensure follow-up visits are provided after acute presentations/hospitalisation.
- Provide access to asthma self-management support after-hours via the internet or telephone.
- Ensure all children with asthma are offered support packages when eligible (e.g. Care Plus, Disability Allowance, Whānau Ora services).
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Adherence</td>
<td>Where a patient takes their medication and follows advice from their health practitioner.</td>
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<tr>
<td>Airways</td>
<td>The passage by which air reaches a person's lungs.</td>
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<tr>
<td>Asthma attack</td>
<td>A sudden worsening of asthma symptoms caused by the tightening of muscles around the airways.</td>
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<tr>
<td>Asymptomatic</td>
<td>Having no symptoms.</td>
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<tr>
<td>Chasm</td>
<td>A profound difference between people or viewpoints.</td>
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<tr>
<td>Chronic disease</td>
<td>A disease that persists over a long period of time.</td>
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<tr>
<td>CME</td>
<td>Continuing medical education provided to health practitioners.</td>
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<tr>
<td>Construct</td>
<td>To make or create a theory by organising ideas, words, etc.</td>
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<tr>
<td>Convergence</td>
<td>Coming together; joining.</td>
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<tr>
<td>Denominator data</td>
<td>Facts about a population.</td>
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<tr>
<td>Ethnicity</td>
<td>The ethnic group or groups that individuals identify with or feel that they belong to. In New Zealand ethnicity is self-identified, and people can identify with more than one ethnic group.</td>
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<tr>
<td>Genetic predisposition</td>
<td>An inherited risk of developing a disease or condition.</td>
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<tr>
<td>Health literacy</td>
<td>The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions, which is influenced by health professionals, health-care organisations and the health system.</td>
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<tr>
<td>LABA</td>
<td>Long acting beta agonists: medications that mainly affect the muscles in the airways. These are slower than SABA to work but last longer.</td>
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<tr>
<td>Likert scale</td>
<td>A scale used to represent people's attitudes to a topic.</td>
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<tr>
<td>Mauri ora</td>
<td>Energy or life force.</td>
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<tr>
<td>NCEA</td>
<td>National Certificate of Educational Achievement.</td>
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<td><strong>Ordinal value</strong></td>
<td>A number that tells the position of something in a list.</td>
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<td><strong>Prevalence</strong></td>
<td>The degree to which something is common; especially: the percentage of a population that is affected with a particular disease at a given time.</td>
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<td><strong>Purposive sampling</strong></td>
<td>Selecting people based on the particular purpose of the study.</td>
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<tr>
<td><strong>Qualitative</strong></td>
<td>Primarily exploratory research used to gain an understanding of underlying reasons and provide insights into the problem.</td>
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<td><strong>Quantitative</strong></td>
<td>Systematic, empirical investigation of observable phenomena using statistical or numerical data or computational techniques.</td>
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<tr>
<td><strong>SABA</strong></td>
<td>Short-acting beta agonists: medications that work within 3–5 minutes mainly to relax the muscles around the airways, resulting in easier breathing.</td>
</tr>
<tr>
<td><strong>Schema</strong></td>
<td>The beliefs and knowledge a person has.</td>
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<tr>
<td><strong>Schema theory</strong></td>
<td>A theory about how people represent and organise knowledge in their long-term memory.</td>
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<tr>
<td><strong>Step-wise</strong></td>
<td>In a series of distinct stages, progressing at each stage.</td>
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<tr>
<td><strong>Sub-optimal</strong></td>
<td>Less than the highest standard or quality.</td>
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<tr>
<td><strong>Tamariki</strong></td>
<td>Child/children.</td>
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<td><strong>Teach-back</strong></td>
<td>A health literacy technique where the health practitioner takes responsibility for, and checks the clarity of their communication by asking their patient to ‘teach-back,’ by explaining or demonstrating what the health practitioner has asked the patient to do.</td>
</tr>
<tr>
<td><strong>Whānau Ora providers</strong></td>
<td>Health providers who focus on whānau as a whole, rather than dealing with individuals. They offer a wide range of services to families and build on their strengths so they can take ownership of their own needs.</td>
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References


## APPENDIX

### Recommendations – Overview

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<tr>
<td>Delivering Understandable Best-Practice Asthma Advice for Māori Children</td>
<td>Using Effective Strategies to Communicate About Asthma with Māori Children</td>
<td>Building Relationships and Working Together to Support Māori Children with Asthma</td>
<td>Health-Care Services That Meet the Health Needs of Māori</td>
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<td>The health system needs to recognise the burden of asthma facing New Zealand society, and Māori children in particular. It must take action to promote widespread public awareness of asthma, and ensure that up-to-date, New Zealand-specific, childhood asthma management guidelines are available to benchmark best practice and ensure consistency of advice.</td>
<td>The health system needs to recognise and promote the importance of health literacy and chronic disease management competencies for all health professionals and other health-care workers involved in asthma management.</td>
<td>The health system must develop a range of health-care personnel equipped to meet the specific challenges of providing chronic disease management for Māori children with asthma. Coordinated development of inter-professional strategies is needed, along with recognition of the roles that asthma educators, pharmacists, non-professional health-care workers, community organisation staff, and trained volunteers can have in supporting the provision of holistic integrated asthma care.</td>
<td>The current system based around reactive, episodic care is failing Māori children with asthma, and is manifesting in significant inequalities in asthma health outcomes. The health system urgently needs to implement a chronic care management model to provide proactive, longitudinal, patient/whānau-centred, culturally responsive care to Māori children with asthma within a multidisciplinary team environment.</td>
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<td>Health organisations need to assume responsibility for the maintenance of best-practice standards within their organisation and for the provision of in-service training of their staff with respect to asthma management. Asthma is a chronic disease; therefore health organisations need to ensure their processes and information systems enable a longitudinal step-wise process of asthma education, which supports the health literacy journey of Māori children and their whānau.</td>
<td>Health organisations need to work collaboratively with the Māori communities to develop high-quality asthma resources and to incorporate these into their educational strategies. Innovative, flexible and community-based asthma educational approaches need to be adopted to better meet the needs of Māori whānau.</td>
<td>Effective asthma care requires a teams approach. Health organisations need to develop and adopt policies and procedures that encourage better interdisciplinary harmonisation, and the strengthening of links with other providers to address the dynamic and holistic well-being of Māori children with asthma. Health organisations must also ensure all staff understand and practise effective ways of engaging with Māori in clinical settings.</td>
<td>Health organisations need to adopt a proactive chronic care management approach to all aspects of asthma support and integrate health literacy policies and procedures into the organisational culture so that every asthma interaction aligns with effective learning outcomes.</td>
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<td>Health professionals need to be able to provide up-to-date best-practice asthma care for Māori children taking account of their age; severity; existing knowledge; learning styles; and cultural preferences of the child and their whānau. All children with asthma should have clear individualised asthma plans, with strategies that encourage health promotion, self-management, and disease prevention.</td>
<td>Health professionals’ teaching strategies need to engage the whānau according to their needs and learning preferences, empowering them to have the confidence to manage their child’s asthma. This involves a requirement for health professionals to undertake specific training in health literacy-based education techniques, chronic disease management education strategies, and cultural engagement.</td>
<td>Health professionals must prioritise the establishment of regular, consistent, trusted relationships with patients, to build a shared understanding of values, priorities, and management strategies. Health professionals need to establish collaborative relationships with colleagues and community organisations to coordinate activities and ensure that asthma education is consistent, timely, and comprehensive.</td>
<td>Māori children with asthma face significant barriers to effective asthma management. It is imperative that health professionals recognise the contribution of structural barriers within health care that contribute to poor health outcomes, and ensure all their patients are receiving eligible supports and benefits.</td>
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## Recommendations – Health System

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| "Promote enhanced public awareness of asthma, its potential seriousness and preventive measures."
| Work in partnership with the education sector to integrate fundamental asthma health knowledge into school curricula. |
| Update New Zealand-specific best-practice management guidelines for paediatric asthma. |
| Develop step-wise learning objectives and a curriculum for asthma management. |
| Fund research that provides evidence for effective asthma interventions that activate and empower whānau to support children with asthma. |
| Influence medical, nursing and pharmacy schools and other health training programmes to teach health literacy and chronic care management to students. |
| Establish and monitor competencies for all health professionals in health literacy education and chronic disease management. |
| Set an expectation within health policies and strategies that all health services will deliver high-quality care that focuses on meeting the health needs and aspirations of Māori children with asthma. |
| Explore models of integrated care to promote closer working relationships between health professionals, and enhanced inter-professional learning opportunities. |
| Improve role delineation for health professional groups in the chronic disease management of asthma in support of a multidisciplinary support approach. |
| Formalise and expand scopes of practice for other health worker roles (such as asthma educators, pharmacists, and community health workers) to support the provision of holistic integrated asthma care. |
| Implement a systematic chronic care management model for asthma care, to provide long-term, proactive, whānau-centred, multidisciplinary support. |
| Develop and support shared information platforms allowing integration of asthma support and monitoring between providers. |
| Align provider incentives so that proactive chronic disease management efforts are rewarded. |
| Allow flexibility within Care Plus eligibility criteria to include asthma as a single qualifying condition. |
| Fund a free annual asthma review in primary care. |
### Recommendations – Health Organisations

<table>
<thead>
<tr>
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- **Health Organisations**

  - Invest in regular in-service training for staff on asthma best practice.
  - Utilise GP patient management systems to provide longitudinal asthma education monitoring.
  - Develop asthma training packages for patients, whānau and communities.
  - Nominate a staff member to the role of ‘asthma champion’ with responsibility for leading uptake of best-practice guidelines, resource implementation, and quality assurance monitoring.
  - Include populations served in the design, implementation and evaluation of health information and services.

  - Work collaboratively with children with asthma to develop high-quality asthma resources for a range of ages and levels of asthma knowledge – particularly interactive and/or audio-visual resources, and resources specifically for Māori children.
  - Develop longitudinal asthma education support and monitoring tools for patients/whānau.
  - Develop community-based, health literacy asthma support and education sessions that are culturally appropriate for Māori children and whānau.

  - Provide policies and procedures for cross-disciplinary harmonisation of asthma management and education.
  - Develop collaborations and provider networks (e.g. within and between DHBs, PHOs, Māori providers, NGOs and other community agencies) to support implementation of best practice for asthma and chronic care management approaches.
  - Mandate the inclusion of cultural competency across the organisation to ensure all staff understand effective ways of engaging with Māori in clinical settings.

  - Develop and implement health literacy policies and procedures for staff.
  - Adopt a proactive chronic care management approach to all aspects of asthma support within organisational policies and procedures.
  - Incorporate a philosophy of culturally competent holistic care into organisational policies and individual consultations with Māori.
  - Contribute to the generation of evidence-informing initiatives to activate whānau and build asthma self-management capabilities.
### Recommendations – Health Professionals

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<td>• Maintain a high level of competency in current best practice for management of childhood asthma.</td>
<td>• Ensure all consultations are seen as opportunities to build health literacy, promote patient activation and support asthma self-management.</td>
<td>• Maintain continuous high-quality relationships to build long-term trust relationships with patients.</td>
<td>• Routinely incorporate chronic care management approaches into asthma consultations, including using proactive strategies to provide preventive advice when patients are well.</td>
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<td>• Ensure all children have access to individualised, understandable asthma action plans.</td>
<td>• Undertake specific training in the use of health literacy-based education techniques.</td>
<td>• Routinely explore the manageability of asthma management plans and utilise relevant support services to address identified barriers.</td>
<td>• Ensure follow-up visits are provided subsequent to acute presentations/hospitalisation.</td>
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<td>• Follow a step-wise education plan when providing asthma support to Māori patients.</td>
<td>• Regularly incorporate a variety of learning media (e.g. interactive/tactile/audio-visual asthma resources) to support asthma education.</td>
<td>• Develop collaborative partnerships with Māori health providers, Whānau Ora providers and other community-based organisations in support of asthma care for Māori children.</td>
<td>• Provide access to asthma self-management support after-hours via the internet or telephone.</td>
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<td>• Provide updated electronic access to asthma plans for whānau, community health workers and schools.</td>
<td>• Continue to develop cultural competency skills for engaging with Māori children and whānau.</td>
<td>• Routinely utilise specialist (medical and/or nursing) respiratory and paediatric expertise to effectively manage those whānau with complex health-care needs.</td>
<td>• Ensure all children with asthma are offered support packages when eligible (e.g. Care Plus, Disability Allowance, Whānau Ora services).</td>
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