



Lessons learned from the ARFNZ Partnership Pilot with Turuki Health Care: Combining school-based screening with in-home assessments to improve asthma diagnosis and management



# Mihi - Sir John Clarke



**E ngā mana, e ngā reo, e ngā karangatanga maha, otira koutou e ngā kaipanui ō tēnei purongo - tēnā koutou, tēnā koutou, tēnā tātou katoa.**

**Tēnā tātou i ngā mate huhua -e ngā mate haere, haere, haere, oti atu.. Kua ea.**

**Ka hoki mai ki a tātou ō te ao tangata e takatu nei i roto i te ao hurihuri. - tēnā tātou katoa.**

Nau mai, haere mai ki tēnei purongo. Ko tōna tikanga he whakaatu i ngā ahuatanga me ngā hua ō te kaupapa i whakahaeretia e Turuki me te Hā Ora Aotearoa e waenganui i ngā whānau i te rohe o Māngere, ki Tāmaki Makaurau.

Ko te tikanga ō te kaupapa, he toro atu ki ngā tamariki me ō rātou whānau e pangia nei e ngā mate ha. I hangaia he kaupapa hei tohutohu hei awhina ia tamaiti. Ko te tino whaingā ka ākona e te tamaiti tau ana, mōnā anake ngā tohutohu hei whakaora i tōnā mate hā.

Ko Turuki he rōpū hauora Māori e mahi piri ana ki ngā whānau roto i te rohe o Tāmaki Makaurau. Ko te Hā Ora he rōpū a motu, he rōpū motuhake. He rōpū tino matatau ana ki te arataki ngā mahi whakaora i ngā mate hā huri noa i te motu.

Ka nui te mihi ki ngā kura me ngā kaiako me ō rātou akonga nā rātou i whakaae mai ki te whakamatautau i te kaupapa nei. He mihi anō hoki ki ngā nēhi nā rātou i hāpai te kaupapa ki waenganui i ngā whānau.

He mahi rangapu tēnei waenganui i ā Turuki te kaiwhakawhiwhi Māori me te Hā Ora Aotearoa. E ai ki ngā tatauranga hauora ko te nuinga ō ngā mea e mau nei i ēnei tumomo mate he Māori, he Iwi nō ngā Moutere ō Te Moananui ā Kiwa a he iwi e noho nei i roto i te poharatanga.

E tino whakapono ana te Hā Ora Aotearoa ko te ara tika hei awhina i ngā mea e pangia nei e ngā mate hā ko te mahi ngatahi a ngā rōpū Māori whakawhiwhi hauora pēnei i a Turuki a me te Hā Ora Aotearoa. Ko ngā rōpū hauora Māori ngā mea e tino matatau ana ki ngā take hauora e pa ana ki ō rātou hapori a ko te Hā Ora Aotearoa te rōpū hei arataki i ngā mohiotanga mō ngā ahuatanga katoa ō te mate hā.

Ngā mihi

**Sir John Clarke**

B.A., Dip. Tchg, CNZM, KNZM

Chief Cultural Adviser, Te Hā Ora: The Asthma and Respiratory Foundation NZ

**Greetings to the various authorities who will have the opportunity to read this report.**

**We pay tribute to our many cherished ones throughout the country who have passed on. We say farewell, farewell.**

**Enough said.**

**Let us now return to the ever-changing world of the living - greetings to one and all.**

Welcome to the readers of this report. The purpose of this report is to discuss the various aspects and outcomes of a joint project that was carried out by Te Hā Ora: The Asthma and Respiratory Foundation NZ and Turuki Health Care in collaboration with families in the Mangere area of Auckland.

The pilot project aimed at reaching out to child sufferers of asthma and their families. Special self-help programmes were constructed for each child with the main goal being to enable each child and their whānau to manage their illness independently and with confidence.

Turuki Health Care is a Māori health care provider working closely with families in the South Auckland region. Te Hā Ora: The Asthma and Respiratory Foundation NZ is a nationally based independent organisation that is skilled in providing leadership in respiratory and asthma health care.

Special thanks to the schools, their teachers and their pupils who agreed to take part in this pilot project. Thanks also to the nurses who liaised with the families.

This has been a collaborative undertaking between Te Hā Ora: The Asthma and Respiratory Foundation NZ and Turuki Health Care the Māori health care provider.

According to the health statistics, the highest number of sufferers of asthma and other respiratory illnesses in New Zealand are those of Māori and Pacific Island descent and those who live in impoverished conditions.

The Asthma and Respiratory Foundation NZ sincerely believes that working collaboratively with community based Māori health care providers like Turuki Health Care who really understand the needs of their communities is the most effective way of helping sufferers of asthma and respiratory illnesses and producing positive outcomes.

Māori health care providers have a close understanding of the health issues within their communities while Te Hā Ora: The Asthma and Respiratory Foundation NZ provides leadership on all aspects of asthma and respiratory illnesses.

Nga mihi

**Sir John Clarke**

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We are grateful to the students and staff of Te Kura Kaupapa Māori ō Waatea, Ngā Iwi Primary School, Southern Cross Campus and Te Kura Kaupapa Māori ō Māngere for participating in the Pilot.

Thank you to the School-Based Health Team nurses and whānau workers at these four schools who worked tirelessly to carry out screening and engage with whānau as part of this project.

We would especially like to thank Sandhu Narain, the Turuki Health Care Asthma Nurse, who went above and beyond the call of duty to engage with schools and whānau and to provide in-house assessments for vulnerable children and their whānau in sometimes challenging circumstances.

Finally, we thank Filippo Katavake-McGrath who project managed the ARFNZ Partnership Pilot with Turuki Health Care and co-authored this informative report with Nick Preval. We thank Nick and Allen + Clarke for their ongoing evaluation support throughout the Pilot.

Letitia O'Dwyer



Chief Executive  
Asthma and Respiratory Foundation NZ

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## Glossary

**Asthma Nurse:** We use this term to refer to Sandhu Narain, a registered nurse whose role in the ARFNZ Partnership Pilot included carrying out in-home assessments and providing education and training to schools and School-Based Health Teams.

**Asthma and Respiratory Foundation NZ (ARFNZ):** A highly regarded, long-standing not-for-profit organisation that has provided education and resources over the past 50-plus years to those affected by a respiratory illness and the health professionals caring for them.

**Child Asthma Action Plan:** A paper tool developed by the Asthma and Respiratory Foundation NZ which records a child's current asthma medication(s) and how and when to administer them. The Plan also includes advice on spacer usage and when to contact emergency services.

**Mana Kidz:** A free, nurse-led, school-based programme operating in 88 primary and intermediate schools in Otara, Māngere, Manurewa, Franklin and Papakura communities that provides comprehensive healthcare for children in the Counties Manukau Health region including rheumatic fever prevention services, skin infection treatment and management, and health assessments. Turuki Health Care delivers Mana Kidz to the four schools participating in this pilot.

**Mōhio:** A clinical information platform owned by the National Hauora Coalition.

**National Hauora Coalition:** A predominantly Māori Primary Healthcare Organisation which includes clinical practices in Auckland, Whanganui and Waikato and provides services to over 200,000 people.

**Nurse Practitioner:** An advanced nursing role that combines nursing and medical knowledge, clinical leadership, scholarship, research, planning and advocacy. Some appropriately qualified Nurse Practitioners can prescribe medicines.

**Respiratory Nurse Specialists:** Registered nurses who are qualified to provide specialised assessment and education regarding respiratory health management, care coordination and patient self-management.

**School-Based Health Teams:** The teams that deliver the Mana Kidz programme: includes nurses and whānau support workers.

**Turuki Health Care:** Turuki Health Care is a trusted South Auckland-based primary healthcare provider with strong roots in the community founded in 1995. Turuki Health Care offers a comprehensive range of health care and social services to around 26,500 people every year.

**Whānau:** In this report we use 'whānau' to refer to whānau Māori, āiga Pasifika, and families from other ethnicities. This reflects the inclusive interpretation of Kaupapa Māori principles which inform the work of Turuki Health Care every day.

## Abbreviations

<b>ARFNZ</b>	Asthma and Respiratory Foundation NZ
<b>AWHI</b>	Auckland Wide Housing Initiative
<b>DHB</b>	District Health Board
<b>NHC</b>	National Hauora Coalition

# Executive Summary

## This Document

This report summarises achievements and lessons from the ARFNZ Partnership Pilot with Turuki Health Care (the Pilot) which was trialled from August 2017 to July 2018. The Pilot combined the expertise and resources of the ARFNZ with the real-world experience of Turuki Health Care in delivering primary health care in Māori and Pasifika communities.

## Rationale

The Pilot was a response to high rates of underdiagnosed and poorly managed asthma and respiratory illness among Māori and Pasifika children and children living in high deprivation areas. The Pilot was designed to overcome barriers to access by reaching out to whānau rather than waiting for them to engage with the health system.





# The Pilot

The Pilot combined school-based screening with in-home assessments for children identified as potentially in need of an asthma diagnosis and/or support with asthma management. The school-based screening initially involved sending home a brief questionnaire to be completed by whānau which included questions about asthma and asked whether whānau would be willing to receive an in-home assessment if required. The in-home assessments were carried out by a dedicated Asthma Nurse. The first in-home assessment provided whānau education and led to referrals, subsequent assessments, and to the eventual development of a Child Asthma Action Plan. Other outputs of the Pilot included educating teachers and School-Based Health Teams about asthma and asthma management and supporting schools to develop Asthma Policies.

The Pilot was delivered via four primary schools in the Māngere area with high proportions of Māori and Pasifika students from high deprivation areas. All four schools were already participants in the Mana Kidz rheumatic fever prevention programme being delivered by Turuki Health Care. The primary goal of the Pilot was that all of the estimated 1100<sup>1</sup> enrolled students would be screened for asthma and respiratory illness via a questionnaire filled out by whānau, and that those children identified as needing in-home assessments and Child Asthma Action Plans would receive them, along with referrals as required. Using a conservative asthma prevalence estimate of 17% derived from New Zealand Health Survey data (Ministry of Health, 2017), at least 187<sup>2</sup> children were likely to be candidates for in-home assessment.

Phase 1 of the Pilot (August 2017 – January 2018) grappled with achieving screening targets, as the initial questionnaire response rates were very low,

for reasons which, based on anecdotal evidence and previous experience, were likely to have included low trust and limited whānau capacity. During Phase 1 in-home assessments were primarily arranged by the Asthma Nurse.

Phase 2 of the Pilot (February 2018 – July 2018) addressed low response rates by screening children at school in the first instance using nurses and whānau workers from the School-Based Health Teams who were delivering Mana Kidz. This approach was implemented from Term Two onwards when rolls were finalised. Whānau of children aged 5-6 were contacted by School-Based Health Team workers via telephone and asked screening questions. For children aged 7-12, participation in the Mana Kidz programme was taken as implicit consent for initial in-school screening which was carried out by School-Based Health Team workers. The whānau of children who were identified as requiring in-home assessment were then contacted by School-Based Health Team workers who attempted to arrange an initial in-home assessment visit by the Asthma Nurse.

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<sup>1</sup> The final combined roll was 1251 students

<sup>2</sup> 213 given the actual combined roll of 1251 students



# What Happened?

During both Phases arranging in-home assessments proved difficult and costly for a variety of reasons, including conflicting whānau obligations, transience and changing phone numbers, low trust and intervention fatigue.

Data collection initially involved paper forms as electronic devices were felt to be a barrier to informal in-home engagement. The Asthma Nurse electronically recorded the details of in-home assessments after visits were completed (initially using Medtech and later using the Mōhio clinical information platform owned by the National Hauora Coalition). By December 2017 tablets provided by Turuki Health Care were trialled as a way to streamline this process. These did not work in the field due to various unforeseen technical issues and the use of electronic devices during in-home assessments was not continued.

Planned linkage of Pilot data with other datasets such as hospitalisation records using Mōhio was not possible in practice and other information which could have been used for evaluation, such as rates of asthma attacks in the four schools, was not recorded consistently by schools. For these reasons, the Pilot focussed on improving screening and in-home assessment rates rather than measuring changes in health outcomes resulting from participation in the Pilot.

The ARFNZ Partnership Pilot with Turuki Health Care screened 994 children (90% of the initial target and 79% of the actual combined roll) and carried out

122 initial in-home assessments (65% of the 187 children predicted to have asthma based on initial roll estimates and 57% of the 213 children predicted to have asthma based on the actual combined roll). 73 additional in-home assessments were completed during the one-year period of operation. 21 children received a Child Asthma Action Plan (17% of those who received an initial in-home assessment). Fifty-nine children were referred to a Respiratory Specialist Nurse.

Asthma Policies were developed and presented to the four schools and each school received two asthma-related training and education sessions. School-Based Health Team workers at all four schools also received asthma-related training.



# Learning

Key lessons from the Pilot include the importance of building on and leveraging existing programmes and relationships with local communities. The Pilot also generated insight into optimal approaches to screening, as school-based screening proved much more effective than sending home screening questionnaires. More generally, the Pilot provided valuable insights into the challenges of improving asthma diagnosis and management for children in communities like Māngere which include the limited capacity of whānau to engage with programmes and services, high levels of transience, and intervention fatigue.

A successful roll-out of an ARFNZ Partnership Programme would need to address the range of barriers to successful management of childhood asthma and leverage the best existing mechanisms in each context in order to make a meaningful difference in the lives of the children who need it most.

# Introduction

Nau mai, malo e tau lava, afio mai – welcome to the report of the ARFNZ Partnership Pilot with Turuki Health Care in Māngere, Auckland. This is our opportunity to share the lessons learned in piloting a school-based programme to screen children for asthma and provide in-home assessments for those that need them.

This report and the ARFNZ Partnership Pilot with Turuki Health Care are guided by the following whakatauki:

Poipoia te kakano kia puawai

*Nurture the seed and it will blossom*

This whakatauki gives life and words to the values that Māori and Pasifika families have believed over thousands of years, that elders are the source of wisdom and future aspiration, adults lead the fulfilment of that wisdom and that children are preparing to breathe new life into the collective.

## Background

New Zealand children have amongst the highest rates of asthma symptoms in the world (Asher et al., 2006): 1 in 7 children have diagnosed and medicated asthma (Telfar-Barnard & Zhang, 2016). The burden of childhood asthma is not distributed equally: the most recent New Zealand Health Survey reported that Māori children had 1.36 times the risk of diagnosed and medicated asthma of non-Māori children, after adjusting for other factors (Ministry of Health, 2017). Children who lived in neighbourhoods with the highest levels of socio-economic deprivation had 1.56 times the risk of asthma of children who lived in neighbourhoods with the lowest levels of socio-economic deprivation, after adjusting for other factors (Ministry of Health, 2017).



Telfar-Barnard and Zhang (2016) report even more extreme patterns of inequality in Māori and Pasifika children's asthma hospitalisation rates. Māori and Pasifika children had 2.6 times the rate of asthma hospitalisation of non- Māori/ Pasifika /Asian children in 2015. The authors also report that people who lived in the highest deprivation areas had 3.7 times the rate of hospitalisations of people who lived in the lowest deprivation areas (Telfar-Barnard & Zhang, 2016).

It is likely that inequalities in asthma hospitalisation rates reflect both higher rates of asthma and poorer diagnosis and management of asthma. Jones and Ingham (2015) cite research showing that Māori children experience higher severity of asthma symptoms and are less likely to have a peak flow meter or an asthma action plan. They note that fewer Māori children are prescribed preventive treatments, which results in poorer overall control (Jones & Ingham, 2015, p.6). There is no comparable research that focusses on Pasifika children in New Zealand or on children living in areas with high levels of socio-economic deprivation in New Zealand, but it is reasonable to assume that similar issues around diagnosis and management also apply.

Ensuring the optimal management and correct diagnosis of childhood asthma is a complex multi-faceted problem in New Zealand. The following are some of the challenges faced by whānau:

- asthma-related GP visits and prescriptions (although free for children aged 0-13) are an ongoing burden in terms of transport costs and time off work to attend appointments;
- other barriers to engaging with primary health care: for example, shame, power relations, cultural inappropriateness;
- differences in health-care services and outcomes of care (Asthma and Respiratory Foundation NZ, 2015);
- high levels of transience (regularly moving home) and other difficult life events which may make ongoing asthma management more challenging;
- need for education about asthma and asthma management (including risks from exposure to cigarette smoke and other environmental factors);
- environmental conditions in the home such as damp, mould and low-temperatures which can trigger asthma symptoms can only partially be influenced by whānau.

Addressing these challenges with targeted solutions can potentially both reduce inequalities and also reduce overall rates of asthma symptoms and costly hospitalisations.

The ARFNZ Partnership Pilot with Turuki Health Care explored one such targeted approach – school-based asthma screening and in-home assessment focused on schools in high deprivation areas with high proportions of Māori and Pasifika students.



# The ARFNZ Partnership Pilot with Turuki Health Care

The ARFNZ identified the value of a partnership approach with a Māori health care provider to better identify and develop community-based solutions that directly reach those most in need. The ARFNZ approached Turuki Health Care and the *ARFNZ Partnership Pilot with Turuki Health Care* (the Pilot), was developed. The Pilot operated from August 2017 – July 2018.

Our organisations saw the value in reaching out to try and improve respiratory health outcomes for vulnerable children, challenging the mainstream traditional health care model which expects those in need to engage with the primary health care system. This approach was informed by *Mā te iwi hei kawe* (people powered), one of the themes of the 2016 New Zealand Health Strategy, and our commitment to improving equity in health.

## Inputs:

ARFNZ provided funding for a nurse and a project manager. In addition, Turuki was also able to access funding for a Respiratory Nurse specialist who:

- assisted with the development of the clinical assessment tools and documentation
- developed information for the schools and parents
- provided specialist intervention and assessment for tamariki with high and complex needs.
- the development of the standing orders for the nursing team and provided the required training on the standing orders to the nursing team
- supervision and oversight of the asthma nurse
- development of policies and procedures for the schools and the school based health team.

Turuki also provided access to some of the health care assistants to support whānau engagement and home visiting with the nurse as required.

The schools have valued the services and support developed which was an added service to the suite of services already provided. Turuki appreciated their willingness to participate in the pilot and to participate in the learning derived from this project.

## High-level outcomes

The Pilot was designed to explore the potential of the combination of school-based screening with in-home assessments by an Asthma Nurse and appropriate referrals to improve the diagnosis and management of asthma for Māori and Pasifika children living in high deprivation areas. More generally, the Pilot tested the partnership model and explored the potential of community-based asthma screening for children living in high deprivation areas.

It was an opportunity for a national-level, mainstream organisation to gain insights into the reality of delivering primary health care programmes in Māori and Pasifika communities and the challenges that such communities face. In order to inform a potential roll-out of the ARFNZ Partnership Pilot across other similar schools in South Auckland and eventually the rest of New Zealand.

It was anticipated that the records of students who participated in the Pilot would be linked to other datasets using the Mōhio platform owned by the National Hauora Coalition in order to assess outcomes such as changes in hospitalisation rates or rates of asthma attacks at school. Assessment of health-related outcomes did not prove feasible for reasons which are discussed later in this report.

## Intended outputs

The ARFNZ Partnership Pilot with Turuki Health Care was originally intended to screen an estimated 1100 children enrolled at four Māngere primary schools for asthma (the actual combined roll was 1251 children). The whānau of children with respiratory symptoms or a previous asthma diagnosis would then be offered an in-home visit from a dedicated Asthma Nurse. Based on asthma prevalence estimates of 17% derived from the New Zealand Health Survey (Ministry of Health, 2017), at least 187 of the estimated 1100 students would be likely candidates for an in-home assessment (213 of the 1251 children actually enrolled).

The in-home visit would include an asthma assessment for the child and asthma education for the child and whānau, and lead to a range of outcomes:

- referrals to GPs or Respiratory Nurse Specialists;
- referrals to other organisations or agencies where appropriate;
- the arrangement of additional in-home visits by the Asthma Nurse; and
- the development of a Child Asthma Action Plan for each child who needed one (it was assumed that each child who received an in-home assessment would ultimately be given a plan unless they already had one).

Other planned outputs of the Pilot included the provision of asthma education to teachers and school-based nurses and supporting the four schools to develop Asthma Policies.





# Pilot Design

ARFNZ and Turuki Health Care worked together to co-design and implement the Pilot. The ARFNZ provided the funding for the Pilot and provided advice, expertise, educational resources, national guidelines and tools such as Child Asthma Action Plans<sup>1</sup>. Turuki Health Care contributed their knowledge of the challenges facing whānau to the design process and leveraged their respected position in the South Auckland community and experience in implementing the Mana Kidz programme<sup>2</sup> to secure the participation of four Māngere schools. Turuki employed two staff for the Pilot – an Asthma Nurse and a Project Manager.

## School-based screening

The Pilot used school-based screening in the form of brief questionnaires sent home to whānau which included questions about asthma and asked whether whānau would be willing to receive an in-home assessment if one was required.

School-based screening was chosen because of the potential to reduce a major barrier to the optimal management of childhood asthma, which is the expectation that Māori and Pasifika whānau will seek help and advice from the primary health care system when their children are experiencing asthma symptoms.

Anecdotal experience and previous research suggested that some whānau, particularly if experiencing economic hardship, might not engage for the following reasons:

- fatigue with navigating government and non-government programmes and systems;
- uncertainty about eligibility for programmes (is my child sick enough?);
- concerns about additional GP or prescription costs;
- experience of GPs not operating in a culturally appropriate or welcoming way;
- shame around outstanding GP fees for adults;
- lack of time and/or other resources due to work and family responsibilities;
- previous experiences of feeling judged
- or lack of empathy

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<sup>1</sup> A Child Asthma Action Plan is a reference tool for children and their caregivers developed by Asthma and Respiratory Foundation NZ. A copy of the Child Asthma Management Plan is available in Appendix 3.

<sup>2</sup> Mana Kidz is a free, nurse-led, school-based programme operating in 88 primary and intermediate schools in Otara, Māngere, Manurewa, Franklin and Papakura communities that provides comprehensive healthcare for children in the Counties Manukau Health region including rheumatic fever prevention services, skin infection treatment and management, and health assessments.

- cultural ideas about asthma being a sign of weakness not ill health; and
- lack of correct information about asthma and respiratory health.

The Mana Kidz school-based programme had previously achieved very high parental consent rates for participation (97%) (King, Moss, & McKegg, 2014), highlighting the potential for school-based asthma screening.

## In-home assessment

In-home assessment was chosen as the best way to engage with children and their whānau because anecdotal evidence suggested that answering probing questions about the health of children in a GPs office or other medical setting was an intimidating experience.

In-home assessment, if done correctly, could reduce intimidation, shift the balance of power and address barriers associated with visiting a GP clinic such as travel costs and time. In-home assessment also provided potential opportunities to address some of the environmental factors which impact asthma such as damp and mould, by carrying out of a brief home assessment and making referrals to organisations such as the Auckland Wide Healthy Homes Initiative (AWHI).

The initial in-home visit was intended to produce the following outcomes:

- initial assessment;
- whānau education about asthma (including potential triggers to avoid);
- referral to GP for follow-up if warranted;
- referral to Respiratory Nurse Specialist if warranted;
- referral to social services if warranted;
- physical assessment of home for asthma risks –referral to AWHI if warranted;
- arrangement of additional in-home visits.

Additional in-home visits were an opportunity to present and discuss a Child Asthma Management Plan developed by the Asthma Nurse and to ensure that whānau understood any new medications prescribed as a result of referrals to a GP or Respiratory Specialist Nurse.

Central to the engagement strategy with whānau was a conversational Kaupapa Māori approach, where the collective agency and mana of whānau is paramount and health professionals work to gain trust and become supportive advisors.

Turuki Health Care also argued that there was no point in an expert going into homes if some of that expertise was not left behind with the families, which drove the educational focus of the in-home assessments.

The Asthma Nurse, Sandhu Narain, was hired because she already had 5 years clinical experience, with a passion for respiratory health and improving outcomes for tamariki and their whānau.

## Location of Pilot

The ARFNZ Partnership Pilot with Turuki Health Care was implemented in Māngere, a suburb of South Auckland which has a high proportion of Pasifika (60%) and Māori (16%) residents and has a lower household median income and rate of home-ownership than that of the combined Auckland region (Auckland Council, 2016). Māngere whānau face housing pressures common to the wider Auckland region such as high rents and scarce accommodation<sup>3</sup>. Homes may be damp, mouldy or cold, any of which can trigger asthma symptoms and cause respiratory illness.

Māngere lies within the Counties Manukau DHB catchment. The DHB has faced challenges in recent years as funding has not kept pace with a rapidly growing population (Counties Manukau Health, 2016). At the time of writing, there is no other programme in South Auckland which uses a school-based setting to screen, assess and provide treatment planning support to children with asthma.

The ARFNZ Partnership Pilot was delivered in four Māngere-based primary schools: Te Kura Kaupapa Māori o Waatea, Nga Iwi Primary School, Southern Cross Campus and Te Kura Kaupapa Māori o Māngere. These schools were primarily selected because of the high proportion of Māori and Pasifika students enrolled and their location in high-deprivation areas. Māori and Pasifika students made up between 95% and 100% of school rolls at the start of the ARFNZ Partnership Pilot.

Children who attend these schools predominantly live in Māngere East, Harania, Aorere, Māngere Central and Favona: high-deprivation areas which face serious economic challenges. The participation of the four schools in the Mana Kidz programme, which was provided by Turuki Health Care via School-Based Health Teams, was another key factor as were other school-specific factors such as high rates of chronic illnesses (one school) or an identified need for asthma education (two schools).

## Data management

Information from in-home visits (assessment results etc.) was initially recorded by the Asthma Nurse on paper because the use of electronic devices was considered to create barriers and alienate whānau. Paper records from events such as screenings, in-home visits, and referrals were then recorded digitally post-visit.

After briefly using Medtech software, the Mōhio clinical information platform was adopted for data management. It was anticipated that this platform would also make it possible (via data linkage) to assess the impact of participation on a range of outcomes including:

- acute GP visits;
- sick days from school;
- recorded asthma attacks at school;
- number of times reliever accessed at school;
- hospital admissions

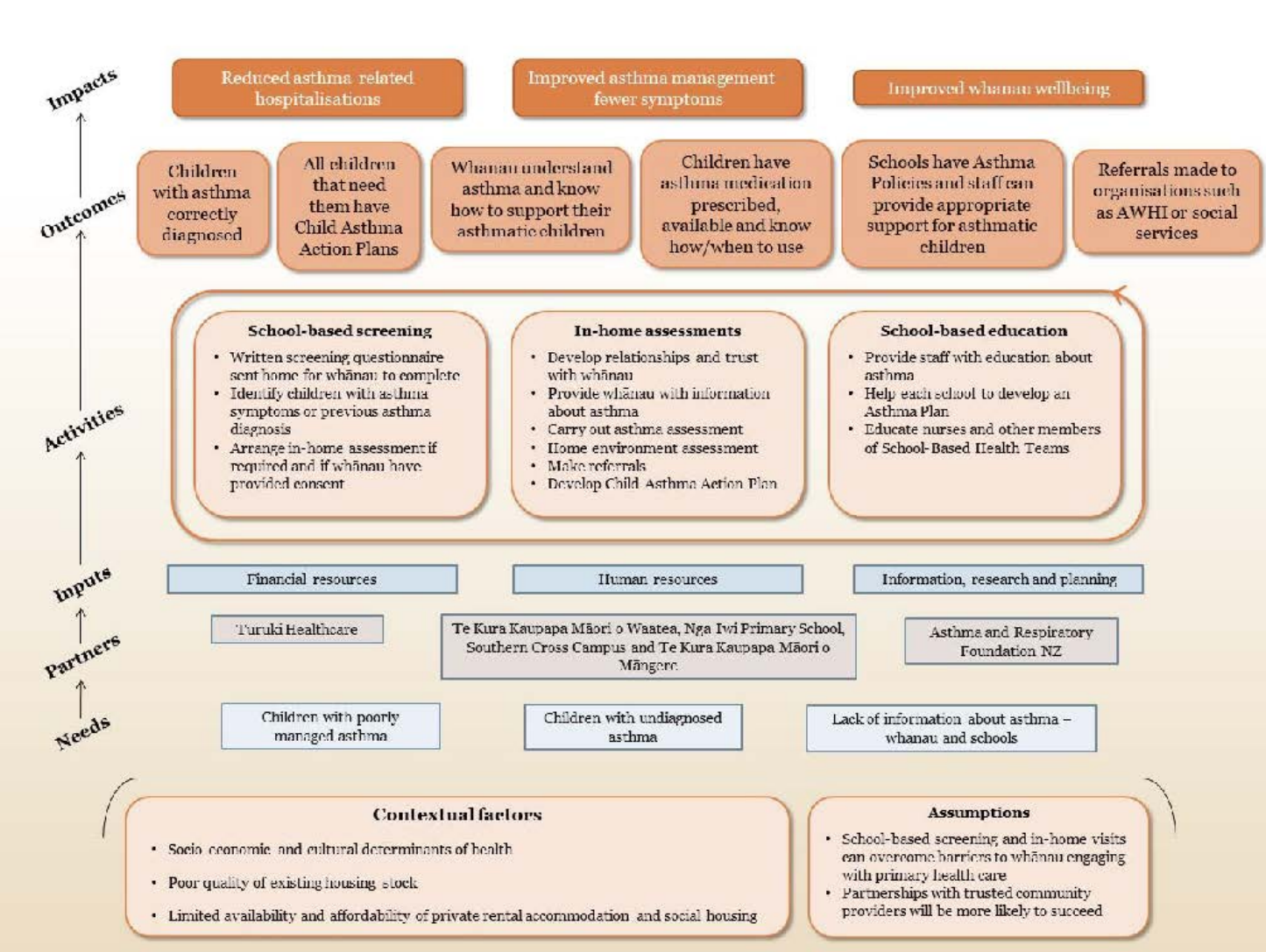
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<sup>3</sup> At the time of writing, the Housing Register listed 271 households at either Priority A or B (Acute or Serious housing need) in the Māngere Ōtāhuhu Local Board Area.

# Intervention logic

An intervention logic was retrospectively developed to illustrate the design and intended outcomes of the Pilot.

Figure 1: Logic model for the ARFNZ Partnership Pilot with Turuki Health Care





Phase One of the ARFNZ Partnership Pilot with Turuki Health Care operated from August 2017 – January 2018. The initial Pilot design required children to take home a screening questionnaire to their whānau. If a child was identified through the questionnaire as having previously diagnosed asthma or current respiratory symptoms, whānau were offered an in-home visit and assessment for the child (if whānau had given consent). Whānau or caregivers who did not consent were contacted in order to confirm that they did not consent and to see if they would reconsider through having the questionnaire and its purpose explained.

The screening and assessment process is presented in Appendix 1.

## Achievements

During Phase One, 261 children were screened (questionnaires completed and returned). Unfortunately, due to issues around the reporting of programme deliverables it is not possible to identify what proportion of the screened children were identified as requiring an in-home visit and assessment. Of the 261 children screened, 72 children received initial in-home assessment visits: in each case whānau also received asthma education. 57 follow-up assessments were also completed. 52 home environment assessments were carried out – the number of referrals to AWHI was not recorded during this Phase. Six Respiratory Nurse Specialist referrals were made.

During Phase One three children received Child Asthma Action Plans. This figure appears low as it was initially assumed that each child who received an initial in-home assessment would ultimately receive a Child Asthma Action Plan (unless they already had one – which no child did in practice). Complicating interpretation, some of the children assessed during Phase One would have received a Child Asthma Action Plan during Phase Two of the Pilot due to the time lag between multiple assessments.

All four schools were presented with Asthma Policies developed as part of the Pilot. The Asthma Nurse delivered two training and education sessions about the symptoms of asthma and ways to recognise and deal with asthma attacks to teaching and administrative staff at each of the four schools. These sessions were gratefully received by staff, who gained greater confidence in dealing with children's asthma. The Asthma Nurse also provided training for School-Based Health-Team Nurses in:

- understanding asthma symptoms in the school setting;
- testing for asthma symptoms; and
- carrying out peak flow and bronchodilator reversibility tests.

# Challenges

## Response rates

During the initial months of Phase One response rates to screening questionnaires were disappointingly low. Over 3,000 questionnaires were distributed. Turuki Health Care took practical steps to increase screening rates such as offering merchandise as an incentive. By November, School-Based Health Team whānau support workers and nurses were assisting the process by opportunistically engaging whānau in person to carry out initial screening and/or to obtain verbal consent. Anecdotally, this produced much greater success rates than the written questionnaires sent home.

## Workload

The workload experienced by the Asthma Nurse was much greater than anticipated. Successfully completing an in-home visit required a great deal of effort to set-up with multiple phone calls. Over the course of Phase One, 125 unsuccessful phone calls and 87 unsuccessful home visits were recorded. During October 2017 alone, 29 hours were spent visiting homes for appointments that were unfulfilled either due to whānau or child being away from home or otherwise unavailable.

## Technology

Technology also presented challenges during Phase One. Tablets provided by Turuki were briefly trialled as a way to record in-home assessment data in real-time, cutting down data-entry time. Unfortunately, the tablets did not work as intended due to various technical issues.

Initial testing also confirmed the belief that tablets and laptops were a barrier to informal in-home interaction style. For these reasons the use of electronic devices to record data in-home was discontinued.

## Data

During Phase One it became clear that anticipated data linkages and baseline data collection using the Mōhio platform were either not practical or not possible. Despite potential future functionality, at the time of the Pilot it was not possible to link participant data with other datasets such as public hospitalisation data using Mōhio.

Another approach explored to measure impact, was to collect the number of asthma attacks and asthma-related sick days recorded by the four participating schools before, during and after the Pilot, and to measure any change. In practice it was found that this information was either not collected or that school record keeping was not consistent enough to make these numbers meaningful.

This meant that it was not possible to undertake a quantitative assessment of the impact of the Pilot on changes in outcomes such as reduced days off school, acute GP visits, or hospital admissions.



Phase Two of the ARFNZ Partnership Pilot with Turuki Health Care operated from February 2018 – July 2018. Towards the end of Phase One it was realised that the current screening model was not meeting targets. To address the issues, Turuki Health Care was able to work with their existing School-Based Health Team workforce who were delivering the Mana Kidz programme to implement an in-school screening approach. The new approach involved screening at a class level. Caregiver consent to participate in Mana Kidz programme was taken as implicit consent to in-school screening for children aged 7-12, which was carried out by the School-Based Health Team. Caregivers of children aged 5-6 were contacted via phone by School-Based Health Team workers to ask the screening questions. In both scenarios whānau were then contacted to arrange initial in-home visits if required. This streamlined approach also reduced the workload of the Asthma Nurse and empowered her to focus on her primary task: the delivery of in-home assessments.

The new screening approach could only be fully implemented from Term Two 2018 because of delays in the confirmation of class lists, which reflects the high levels of transience and instability experienced by many children who attend the four schools.

This was a known issue based on previous years' experience delivering Mana Kidz and meant that until the start of Term Two the Phase One Screening approach was continued.

The screening and assessment process is presented in Appendix 2.

## Achievements

During Phase Two, an additional 733 children were screened, primarily by the School-Based Health Teams. The rate of screening per month greatly increased relative to Phase One (from 43 children screened per month to 122, although this crude comparison does not factor in the proportion of time during the two phases that was term time, or the cost of the resources used).

During Phase Two, 50 children received initial in-home assessments. In each case whānau also received asthma education. During Phase Two 73 follow-up assessments were also completed. Over 30 home environment assessments were carried out leading to 15 referrals to AWHI or similar organisations and 53 referrals were made to Respiratory Nurse Specialists.

18 children received Child Asthma Action Plans during Phase Two (some of which may have resulted from visits and assessments carried out during Phase One).

One School-Based Health Team reported finding the My Asthma App developed by the Asthma and Respiratory Foundation NZ valuable in supporting screening and whānau education (unsolicited communication).

Two individual stories have been included to make the challenges faced by children and the benefits of the Pilot more tangible. We have changed some of the details presented below to protect the privacy of the children and their whānau.

## Story 1

One girl visited by the Asthma Nurse was waking most nights coughing – sometimes she would even vomit, according to her mother. She was living with daily wheeze, could not participate in exercise, and regularly missed school during winter. The whānau home was damp, mouldy and cold – cold is a particular asthma trigger. Her parents knew that she had asthma and had taken her to see the GP before, but believed that her day-to-day symptoms were normal for an asthmatic. Asthma greatly impacted this girl's life and that of her family – her mother stayed up at night to deliver the "blue inhaler" at 3am and was exhausted and distressed as she was also looking after the girl's younger siblings.

During the course of multiple visits and follow-up phone calls, the Asthma Nurse was able to educate the girl's whānau about asthma management and to explain that the girl's experience was not normal and was potentially putting her life at risk and damaging her lungs. Referrals to a Respiratory Nurse Specialist and GP visits led to the prescription of correct medicines, including an anti-leukotrine, and greatly reduced symptoms. The whānau was also referred to AWHI. Multiple conversations with the Asthma Nurse were required to change whānau thinking about asthma.

One of the interesting specific ways that the Asthma Nurse was able to help the girl and her whānau was to advocate with the school for her to wear warm clothes during class time at school to reduce the impact of the cold. Her school had previously not understood the importance of letting this child wear her coat inside.

## Story 2

One boy visited by the Asthma Nurse was suffering from "low breath" and struggling to play his favourite sports. He coughed in the morning and night, when he laughed, and suffered continuous nasal congestion. The whānau home was cold, damp, and mouldy and his father smoked indoors.

The Asthma Nurse's initial assessment led to a referral to a Respiratory Nurse Specialist and to multiple additional in-home visits. Some members of his whānau were initially opposed to the use of a preventer when it was suggested, believing that this could lead to "weakness". Over the course of six visits the boy's whānau came to accept the value of appropriate medication, which greatly increased his compliance and led to reductions in his symptoms. Indoor smoking stopped and a referral to AWHI was made in order to try and address the cold, mould and damp. The whānau also purchased appropriate heaters with some assistance.

The Asthma Nurse's notes state that, "education has been the key in this case – educating in small amounts so that it's not overwhelming and re-educating at each visit things like the heating, sleeping arrangements, smoking and temperature indoors".



# Challenges

## Response rates

While the in-school screening carried out by the School-Based Health Teams greatly improved the screening rates, the proportion of children who received an initial in-home assessment who ultimately received a Child Asthma Action Plan assessment continued to be low during Phase Two. These challenges, and potential solutions, are discussed in greater depth in the following section of this report.

## Workload

The School-Based Health Teams at the four schools experienced some challenges because of the extra workload that assisting the Asthma in School Pilot placed on workers. Ultimately workers were willing to take on additional tasks to support the children in their care for altruistic reasons, but the additional workload would not have been sustainable without additional resources over a longer period of time.



# Lessons for the Future

The ARFNZ Partnership Pilot with Turuki Health Care highlighted the challenges of providing primary health care programmes to children and their whānau in areas such as Māngere. A great deal was learned from the Pilot, which can strengthen a future ARFNZ Partnership Programme and ensure that we are reaching those most vulnerable.

## Strengths

### Leveraging existing infrastructure and relationships

Screening rates increased when the School-Based Health Teams already in place at the four primary schools were asked to reach out to whānau with the support of standardised educational resources, national guidelines and direction from ARFNZ. Screening rates increased greatly at the start of term two of 2018, when in-school screening was implemented using the resources of the School-Based Health Teams. This success built on the work already done under the Mana Kidz programme to build trust and credibility with the community.

### Building trust

During the course of the Pilot signs of increasing trust were seen from the local community. When the Asthma Nurse was able to gain access to the homes of participating whānau, she was able to gently and respectfully discuss asthma and respiratory health.

Over multiple visits she found that, as families became more familiar with her, they became increasingly confident and began to ask more questions. Over time caregivers' confidence in the Asthma Nurse grew, to a point where networks of caregivers began recommending her to other whānau with children at the same school. The following quote from the Asthma Nurse illustrates the value of trust:

*I was visiting a mother at a kohanga reo to access a child attending Te Kura Kaupapa ō Māngere for an assessment. When I was chatting to the mother, I found out about two more siblings and she asked me to conduct assessments for them. During my chat with the mum, three other mums whose kids all attended [school] all asked me to assess their children while I was there doing the first child. This led to six assessments when I had only expected there to be one. Also, one of those mums had previously not responded to any of my calls, and she said to me that if the other mums were confident in me, then I was alright.*

## Staff

The team worked tirelessly to engage whānau and to help children in challenging circumstances. The Asthma Nurse's expertise in navigating complex multi-cultural situations with grace and kindness was reflected in the trust that the Pilot built.

## Partnership, collaboration and linkages

The partnership approach between the ARFNZ and Turuki Health Care was a strength of the Pilot, combining the knowledge, experience, educational resources, tools and national guidelines provided by the ARFNZ with Turuki Health Care's real-world knowledge and credibility.

A particular strength of the partnership was the flexibility of the funding provided by ARFNZ, which allowed the Pilot to adapt to challenges faced in real-time, generating better results.

The relationship between Turuki Health Care and the NHC led to the use of the Mōhio clinical information platform, which has potential to inform the outcome evaluation of a future ARFNZ Partnership programme when partnering with other health providers who use this platform. Other valuable relationships that strengthened the Pilot included links between Turuki Health Care and AWHI that were originally developed during the Mana Kidz programme.

## Challenges

The ARFNZ Partnership Pilot with Turuki Health Care faced challenges at each stage of the intervention process. Understanding and documenting these challenges is vital if future community-based asthma partnerships with Māori health care providers are to meaningfully improve the diagnosis and management of our children's asthma.

### From screening to in-home assessment

Although Phase Two of the Pilot achieved much greater screening rates, arranging in-home assessments remained challenging throughout the programme. Many phone calls were required to successfully arrange a visit, and in many cases, despite having gained caregiver consent, it was not possible to successfully complete an in-home visit.

Most failed attempts to contact caregivers occurred when making contact by phone, however some failed attempts happened on arriving at the home. Some whānau were not home at the time of appointments, and in some cases whānau refused to let the Asthma Nurse in. Other reasons for missed appointments included changes in cell phone numbers and high levels of transience – moving regularly and not keeping schools informed of changes.

The Asthma Nurse worked with whānau or caregivers to try and understand why they might not want to participate in the Pilot. Some felt that the programme was invading their personal space and family routine while others did not feel informed about the procedures.

Some whānau suffered severe circumstance changes which created household stresses and some whānau were too busy with other commitments to attend appointments. Whānau also reported "intervention fatigue". Many of the whānau of the children in the four schools already have extensive interactions with government agencies and other programmes.

The phenomenon of "another car up the driveway" can be dispiriting, contributing to the alienation and shame that can be experienced in interactions with external agencies as well as placing a cumulative burden on whānau in terms of time and administration.

Overcoming fears about judgemental and interfering agencies is a challenge for any organisation that wants to deliver primary health care programmes in communities like Māngere.

The informal in-home approach was specifically designed to address these barriers, but it still proved difficult to quickly develop a brand and reputation that was trusted and distinct in order to “get a foot in the door”.

### **From in-home assessment to better asthma management**

Once the Asthma Nurse successfully completed an initial in-home visit and assessment there were still barriers to better asthma management at each of the following subsequent steps:

- attendance at appointments (GP or Respiratory Nurse Specialist)
- medication prescribed and obtained (requiring a GP or Nurse Practitioner);
- successful arrangement and completion of additional in-home visits by the Asthma Nurse;
- completion of a Child Asthma Action Plan; and
- addressing conditions in the home that could trigger asthma symptoms.

Informal discussion with whānau or caregivers confirmed that barriers to GP appointments and obtaining prescriptions such as travel time and costs, and outstanding adult GP fees must also be understood and explored. Other specialist appointments and referrals faced many of the same barriers. The impact of referrals to AWHI, intended to address damp, mould or low-temperatures in the home, remains unknown, but it is likely that many of the barriers described above also limited the success rate of such referrals.

Ultimately, of the 122 children who received initial in-home assessments (72 in Phase One and 50 in Phase Two) only 21 (17%) received completed Child Asthma Management Plans – in an ideal world the vast majority of these children would have received a Plan. This demonstrates the many barriers that the Pilot faced at the key steps described above: attendance at appointments, and successful completion of additional in-home assessments.

### **Data and data management**

The Pilot experienced a number of data and data management challenges. The tablets briefly trialed for recording information including in-home assessments did not function as expected and both tablets and laptops proved to be barriers to informal in-home assessments when tested.

A future programme would need to consider trade-offs between the barriers that technology may create in an in-home assessment context and the additional time costs imposed if data is recorded on paper and later rerecorded electronically.

If tools for recording data such as tablets are to be used, they need to work seamlessly in a variety of contexts and to be as inobtrusive as possible in an informal interview setting.

Although it was originally considered possible to link children’s data with other datasets via Mōhio for evaluation purposes, this did not prove to be the case. A future programme would need to have a clearer vision of what information is most useful and feasible to collect and use for evaluation purposes. To ensure high-quality and complete data, workers in the field who record data need to be trained and provided with appropriate resources for data collection and time must be allocated for data entry. Baseline data collection and the selection of non-participant schools as comparators need to be considered if quantitative evaluation is to be meaningful, as does sample size.

## The way forward: lessons learned

The ARFNZ Partnership Pilot with Turuki Health Care was an exploration of the potential of a community-based programme to address poorly managed or undiagnosed asthma and respiratory illness among Māori and Pasifika children living in high deprivation areas who are known to experience very high rates of asthma. The Pilot demonstrated both the need for this work and the challenges that must be overcome to help children experiencing asthma and respiratory illness.

We are confident that a targeted Partnership Programme, delivered first in areas of high need, can build on the lessons of the Pilot and achieve positive change for New Zealand by improving the diagnosis and management of our children's asthma. A fit-for-purpose programme should have the following characteristics.

### Trustworthiness

The programme must build a strong brand to overcome low levels of trust. This cannot be achieved quickly: the programme will only succeed if it can develop a positive reputation and strong relationships with local communities over time, which in turn requires consistent funding.

### Partnerships

It is vital that the programme work with existing trusted community-based programmes and providers. This will allow it to leverage knowledge, trust and skills developed on the ground rather than to start from scratch as yet another organisation/programme that whānau must understand and negotiate.

### Focus on community-based delivery and the ability to prescribe asthma medication within this environment

The challenges faced by the Pilot in progressing from screening to successfully completed in-home assessments and subsequent appointments suggest that delivering as much of the programme in a community environment as possible is likely to produce better outcomes. For example, if it is possible to employ dedicated Nurse Practitioners across a region who are able to formally assess children at school (or another community location) and prescribe asthma medication, the major barrier of GP visits could be reduced or eliminated. Providing asthma medication via schools or another appropriate community location could also greatly improve asthma management if feasible.

### Reaching whānau

In-home assessments are not suitable for all whānau or caregivers. The programme must engage across a range of settings. This could include group-based education sessions delivered to whānau as part of, or linked to existing programmes or activities, in appropriate locations such as marae, churches or schools.

### Resources

A successful programme will provide fit for purpose tools for data recording and management and funding for workers that reflects the time and other resources needed to enable successful engagement with communities that face significant challenges.

## Timing

We believe that commencement of a project in a school setting is best at the beginning of the year when there tends to be a high level of engagement of whānau with consents and interaction with the school.

## Complexity

Initially we saw the process as lineal and sequential with a few points of engagement prior to being able to develop the plan. However the level of complexity meant a higher degree of monitoring and reassessment over a longer period of time than anticipated.

## Sustainable funding

**Asthma affects 1 in 7 children in New Zealand and Counties Manukau has one of the highest rates for those aged 0-14 years. There is still no funding dedicated to combatting this.**

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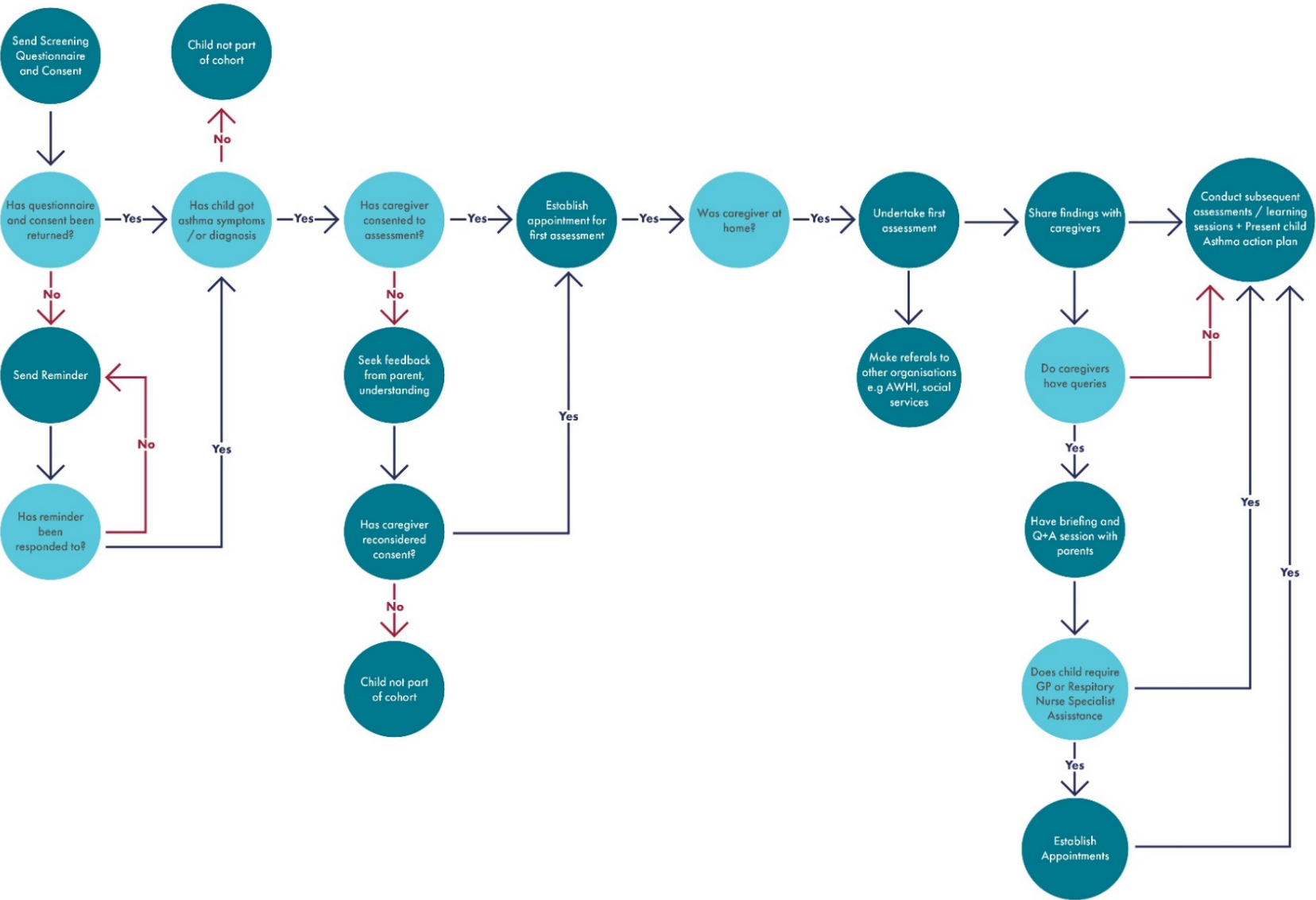
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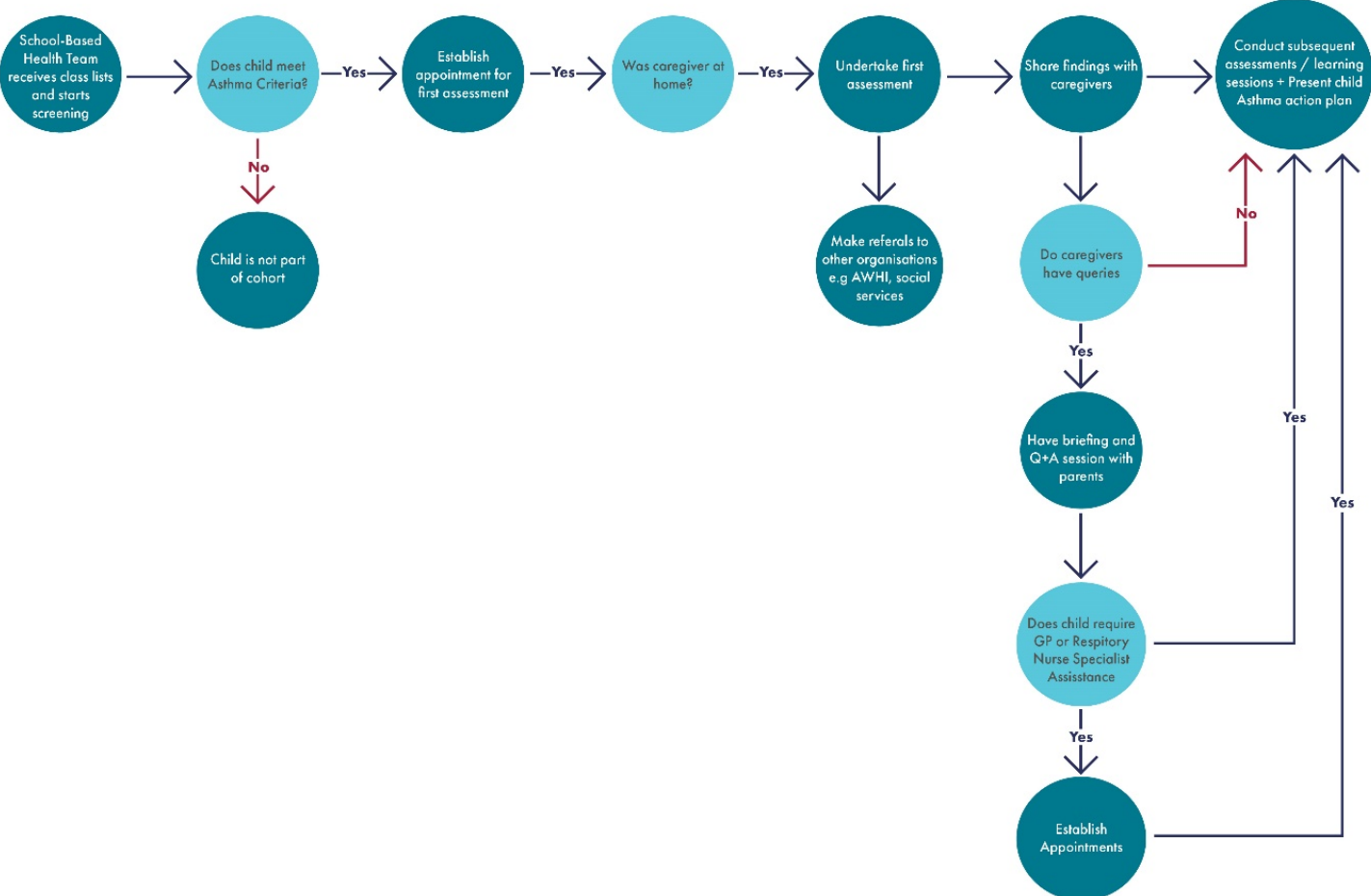
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# Appendix 1: Phase One Screening and Assessment Process





# Appendix 2: Phase Two Screening and Assessment Process



# Appendix 3: Child Asthma Action Plan

## Using a spacer

## How to care for your spacer

## Asthma + Respiratory

FOUNDATION NZ

If you use a metered dose inhaler (MDI), a spacer will help to get the right dose of medicine into your lungs. Your doctor can give you a spacer for free. Remember not to share your spacer with anyone else, and ask for a new one every year.

- 

1. Hold the inhaler upright and give it a good shake
- 

2. Fit the inhaler into the opening at the end of the spacer
- 

3. Seal the lips firmly around the mouth piece - press the inhaler once only
- 

4. Take 6 slow breaths in and out through your mouth. Do not remove the spacer from your mouth between breaths
- 

5. Remove the spacer from your mouth. Repeat steps 1-4 for further doses

• Younger children will need your help to follow these steps  
 • Children under the age of four can use a mask with the spacer

- 

1. Take the spacer apart (both the small and the larger spacer dismantle into 2 pieces)
- 

2. Use warm water with a little dishwashing liquid and hand wash your spacer
- 

3. Do not rinse or wipe the spacer. Leave the pieces on the side to dry
- 

4. Put the spacer back together

## Child Asthma Action Plan



Produced by the Asthma and Respiratory Foundation NZ

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 🌐 asthmaandrespiratory.org.nz

Updated Aug 2017 - ASTH10

Name: \_\_\_\_\_

Better breathing, better living



### Well

**When I'm well:**

- I have no cough
- I play just like other children
- I use my reliever puffer less than 2 times a week

**My puffers are:**

**Preventer:** I take this every day even when I'm well.  
 The name of my preventer is \_\_\_\_\_ The colour is \_\_\_\_\_  
 I take \_\_\_\_\_ puffs in the morning and \_\_\_\_\_ puffs at night through a spacer.

**Reliever:** I take this only when I need it  
 The name of my reliever is \_\_\_\_\_ The colour is \_\_\_\_\_  
 I take \_\_\_\_\_ puffs through a spacer when I wheeze, cough or when it's hard to breathe.

If I find it hard to breathe when I exercise I should: Take \_\_\_\_\_ puffs of my reliever



### Worse

**When my asthma is getting worse:**

- I cough or wheeze and it's hard to breathe, or
- I'm waking at night because of my asthma, or
- I cough or wheeze when I play, or
- I need my reliever inhaler to control my asthma more than 2 times per week

**If my asthma gets worse I should:**

Keep taking my preventer every day as normal and take \_\_\_\_\_ puffs of my reliever every 4 hours  
 If I'm not getting better doing this I should see my doctor today

**Contact:**



### Worried

**My asthma is a worry when:**

- My reliever isn't helping, or
- I'm finding it hard to breathe, or
- I'm breathing hard and fast, or
- I'm sucking in around my ribs/throat, try looking under my shirt
- I'm looking pale or blue

- Sit me down and try to stay calm
- Give me 6 puffs of reliever through a spacer, taking 6 breaths for each puff
- If I don't start to improve I need help now** →

### Emergency

**DIAL 111 and ask for an ambulance**

**WHILE YOU'RE WAITING:**

- Try to stay calm and keep me sitting upright
- Give 6 puffs of reliever through a spacer every 6 minutes with 6 breaths for each puff until help arrives

Date Prepared: \_\_\_\_\_ Doctors Signature: \_\_\_\_\_ Plan to be reviewed when treatment changed



**Asthma  
+ Respiratory**  
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