

New Zealand Child
Youth Clinical Networks

Annual Report 2022-2023



The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa



New Zealand Child & Youth
Clinical Network



Contents

- Message from the Chair 4
- About New Zealand Child and Youth Clinical Networks (NZCYCN) 6
- Achieving Equity 7
- Our Networks 10
- A Season of Change 12
- Paediatric Allergy Clinical Network 14
- Clinical Network for Child Protection 16
- Clinical Network for Children and Young People with Diabetes 18
- Child and Youth Eczema Clinical Network - Te Rōpū Kiripai Hapori 20
- Child and Youth Clinical Network for Gastroenterology Services 22
- Paediatric Neurology Clinical Network 24
- The Paediatric Palliative Care Network 26
- Newborn Clinical Network 28
- Paediatric Sleep Medicine Clinical Network 30
- KidsHealth 32
- Our People 35

Poipoia te kākano
kia puawai

Nurture the seed and
it will blossom

Message from the Chair

Kia ora tatou,

Ko Nicola Austin toku ingoa. I am a paediatrician in Ōtautahi, Christchurch, and have taken over as Chair of the Clinical Networks from Professor Dawn Elder in December 2022. My sincere thanks go to Dawn for her leadership and development of the networks and for furthering the Society's strategic plan. Her contribution has been significant for all the networks, especially in her special interest, the Sleep Network.

Over this last year, we have contracted two important positions since the development of Te Kāhui Mātai Arotamariki o Aotearoa, the Paediatric Society of New Zealand's strategic plan for 2021. Our Māori Director, Wane Wharerau, provides tikanga and connections from his impressive background and mana. Renee Smith-Apanui held the Māori Programme Manager position until June 2023. Now, Jontel Kiwi Kiwi has stepped into the role. She has progressed from information gathering to developing a Tiriti Critical Analysis Tool for assessing network activity and projects.

Developing and enhancing two networks has occurred in the first six months of 2023. The Respiratory Network has developed from the Cystic Fibrosis Network. This will enable the needs of children with respiratory conditions, the most common reason for hospital admission, and to focus particularly on those conditions that are higher in Māori and Pacific tamariki.

The Cerebral Palsy Network, led by Paediatric Orthopaedic Surgeon Dr Sue Stott and the Child Development and Disability Network, co-chaired by Associate Professor Fi Graham (OT) and Developmental Paediatrician Dr David Newman, ended in June 2023. A new Neurodevelopment Network was established on 1 July 2023. We are hugely grateful for the work of the two networks. We welcome co-chairs Dr Collette Muir and Denise Janes, who are setting up a new reference group. Cerebral Palsy will become a workstream in the new network to continue their mahi.

Both networks will have leaders, a project coordinator and a reference group of 8 to 12 clinicians and consumers. The membership of the networks will be open to a wide group, and Neurodevelopment will replace the Child Development Special Interest Group. This signals a more inclusive structure for networks.

Palliative care guidelines were extensively updated and enhanced in 2022, culminating in their placement in December on the NZCYCN site on the Starship Children's Hospital platform via [dedicated web pages](#). This was supported by project funding from the clinical network budget. A change in leadership of the network has occurred in 2023, and we welcome Dr Amanda Evans from Wellington to the Clinical Leaders Group.

The Governance Group for the networks has endorsed the Code of Expectations HQSC¹ for consumer involvement. It signals the value placed on meeting the needs of tamariki and whānau being at the centre of our mahi. Noting that we view consumers as the 'voice of children and youth'.

We have recently welcomed new governance members: Daniel Gotz from Te Aka Whai Ora and Dr Christine MacIntosh, who currently has a GP liaison role in Auckland.

The future of our networks and over 30 national networks within Hospital Specialist Services is under a new and developing framework. We have been engaging with the leaders of this mahi and have signalled our willingness to contribute and develop within the new structure.



Nicola Austin

Chair of the Clinical Networks

The achievements to date of the clinical networks allow the Paediatric Society to influence the direction for tamariki and rangatahi, especially those with complex and chronic conditions.

However, there are a significant number of clinical paths outside our work, particularly existing networks such as Cardiac and Children's Oncology and care provided at Starship and the main regional districts. Scoping what the future holds is now underway. We will keep you informed and engaged as progress unfolds.

The networks have outlined their individual achievements in this annual report, and I thank all participants for their mahi and contribution.

¹ Equally Well | Physical health equity. Te Pou. URL: <https://www.tepou.co.nz/initiatives/equally-well-physical-health>

About New Zealand Child and Youth Clinical Networks (NZCYCN)

Clinical networks are made up of experienced child health professionals and consumer representatives from across the health sector who work collaboratively to provide leadership, resources and best practice recommendations for child health in Aotearoa.

The NZCYCN programme prioritises activities towards achieving equitable access to healthcare and health outcomes for all tamariki and rangatahi.

Clinical networks are guided by the Child and Youth Clinical Network (NZCYCN) Governance Group and PSNZ Executive. Networks align with the 2021-2026 PSNZ Strategy with its main principles of equity, partnerships and connectedness, people/ngā tangata, and improving practice.

Throughout the 2022/23 year, there were 12 clinical networks with a focus on a wide range of specialty areas. Broadly, all networks aim to provide health professionals with the resources to improve practice and to promote the delivery of equitable child and youth health services that improve health outcomes for all tamariki and rangatahi.

Clinical networks work closely with the KidsHealth team and others to develop tools and resources empowering whānau to partner with their healthcare teams in decision-making for their tamariki and rangatahi.

Clinical networks also provide a national voice to promote service improvements where child health issues and gaps are recognised in health service provision. This can be through submissions and consultation with Government and other healthcare providers.

Many of the networks have developed unique strategies to support professional and consumer education, such as Q and A sessions on Facebook Live in partnership with Well Child Tamariki Ora. Collaboration with other health sector organisations has been a key theme this year, enabling broader reach and connection within child health.

Further information on each of our networks can be found on **pages 14-31** of this Annual Report.

Achieving Equity

Introducing our Māori Director and Programme Manager Te Tiriti o Waitangi and Equity



Wane Wharerau
Ngāpuhi

Māori Director Te Tiriti o Waitangi and Equity

Wane recently resigned from the NZ Police after 42 years of service, beginning his career at 18 years old in Dunedin. He held several roles throughout the country in rural and urban settings and served communities in the Waitemātā region as the Waitākere Iwi Liaison Officer.

His work collaborating with Iwi within the NZ Police has positioned him well to bring his expertise to the role of Māori Director with Te Kāhui Mātai Arotamariki o Aotearoa. Wane brings 25 years of experience in Governance in both Māori and mainstream organisations.

A second role that Wane currently holds is Chair of the country's largest iwi, Ngāpuhi. Te Tiriti o Waitangi was created in the North Island and was written in the Ngāpuhi dialect. Wane has an intimate and familial link to several of the key signatories of Te Tiriti.

Te Tiriti has significant meaning to Wane, his iwi and Aotearoa as the founding agreement between Māori and the Crown. Wane emphasises the spiritual significance of the document to Māori and Tangata Tiriti in bonding all people together as a great country.

Wane cares for Aotearoa and its people and is focused on making a difference in our future. A healthy Māori and Pasifika population means more economic and social efficiencies for Aotearoa.

He is passionate about his work with Te Kāhui Mātai Arotamariki o Aotearoa and appreciates that the team also have the same strong desire for improving outcomes for Māori and all our communities.



Jontel Kiwi Kiwi

Ngātiwai, Ngā Puhi, Ngāti Hine,
Waikato-Tainui

Programme Manager Te Tiriti o
Waitangi and Equity

With a background in naturopathy, rongoā Māori, population health and community engagement, Jontel brings her experience in primary healthcare and passion for elevating whānau voice to the organisation.

She believes that kotahitanga/ collaboration is the cornerstone for achieving equity for tamariki, rangatahi and whānau Māori, and Aotearoa as a whole.

Jontel is excited to facilitate the building of connections between whānau, kaimahi and Te Kāhui Mātai Arotamariki o Aotearoa to ensure whānau is at the centre of all future mahi.

Te Tiriti o Waitangi

Tiriti o Waitangi is the overarching framework for Te Kāhui Mātai Arotamariki o Aotearoa Strategic Plan 2021-2026.

Historically, and at present, as a nation, we have been in a state of disconnect from Te Tiriti o Waitangi across the spectrum of worldviews and life experiences. This manifests into disparate outcomes for Māori, spanning the social determinants of health and societal systems that best serve those born into relative advantage, thus perpetuating the cycle of inequity. And while many colleagues may ardently support a changing rhetoric, a common thread of this disconnection is the lack of tangible processes to apply Te Tiriti to everyday life, specifically to settings within the health sector.

Equity

Under Te Tiriti o Waitangi, equity for Māori is guaranteed; therefore, the responsibility for driving equity lies firmly within the remit of present generations to deliver outcomes urgently and for our mokopuna to come. Te Kāhui Mātai Arotamariki o Aotearoa has taken steps to be a driving force for ensuring equitable health outcomes for tamariki, rangatahi and their whānau through the following measures, all of which will be developed collaboratively into the future.

Te Rauemi Tiriti - Critical Tiriti Analysis Toolkit

In an absolute commitment to the Strategic Plan 2021-2026, Te Kāhui Mātai Arotamariki o Aotearoa (PSNZ) has developed a tool kit called Te Rauemi Tiriti, based on Critical Tiriti Analysis work by Came, O’Sullivan, Kidd and McCreanor (2023) which through a series of questions guides users to apply each article of Te Tiriti to their work programme, ensuring the articles are being upheld and areas for improvement are identified for inclusion.

In the first instance, Te Rauemi Tiriti has been introduced and applied to the annual workplans of four clinical networks: Respiratory, Diabetes, Neurodevelopment, and Palliative Care. The intention is to refine the tool for use across



all clinical networks and work collaboratively to support equitable outcomes and build meaningful relationships with Tangata Whenua.

Ngā Rauemi Tiriti has been adapted for use across the Society’s suite of work, including grant and funding applications and reporting, terms of reference, strategy and policy, processes, and projects, with the provision that it will be continuously improved, reviewed, and adjusted to ensure its relevance and accuracy in achieving equitable outcomes for tamariki and rangatahi Māori and their whānau.

Preserving Te Reo Māori

Te Reo Māori is a tāonga, and as such, Te Kāhui Mātai Arotamariki o Aotearoa actively promotes its inclusion on the website and through a new process that gifts clinical networks a name that exemplifies their mahi and invites connections between the membership and Tangata Whenua. Te Reo Māori has an incredible depth where each sound and word has a whakapapa or origin that links to the whole. The inclusion of this tāonga in our communications does not fully emanate its mauri (essence) but serves as the welcoming of a language that has long been expelled from our identity as a nation of Māori and Tangata Tiriti.

The Māori Rōpū

A rōpū for Māori health professionals’ was established to support and connect Māori healthcare providers in paediatrics. All Māori members of PSNZ and all Māori senior clinicians are welcome to join, with meetings held every 1-2 months. The group’s primary role is to provide support to Māori fellows in paediatrics, fostering a sense of manaakitanga and whakawhanaungatanga among the few Māori practitioners in Aotearoa specialising in paediatrics. We also aim to mentor all Māori trainees in paediatrics in all disciplines.

Diversifying Membership: Māori Scholarships Initiative

To promote diversity in PSNZ membership, funds from the Māori rōpū will cover PSNZ membership fees for specific Māori healthcare professionals in paediatrics, including trainees (registrars or house surgeons), pediatric nurses, and allied health workers. This initiative may also facilitate connections with Māori community organisations involved in caring for Tamariki Māori.

Our Networks

- Paediatric Allergy Clinical Network
- Clinical Network for Child Protection
- Clinical Network for Children and Young People with Diabetes
- Child and Youth Eczema Clinical Network - Te Rōpū Kiripai Hapori
- Child and Youth Clinical Network for Gastroenterology Services
- Paediatric Neurology Clinical Network
- Paediatric Neurodevelopment Network (Previously Child development and disability, Cerebral Palsy)
- Newborn Clinical Network
- Paediatric Sleep Medicine Clinical Network
- Paediatric Respiratory Network (previously Cystic Fibrosis)
- Paediatric Palliative Care Clinical Network

Our Vision

Tamariki in Aotearoa flourish in health and wellness.

Our Impact

- National reach** to deliver consistent, equitable child health services and outcomes for tamariki and rangatahi
- KidsHealth information** empowers whānau to support tamariki and rangatahi to flourish in health and wellness
- Well engaged and informed child health workforce** across the spectrum of child health service delivery

Our Strategic Priorities

Equity

Improve access to healthcare and outcomes for all tamariki and rangatahi, including Māori, Pasifika, disabled and other populations impacted by structural barriers

Partnerships and Connectiveness

Work with networks across the sector that impact tamariki health and wellness

People; Ngā Tāngata

Promote health workforce development and ensure whānau voice

Improving Practice

Enable national quality improvement in child health

How we achieve change

- Promote** change to address equity and improve child health outcomes
- Identify gaps** in service provision and make recommendations nationally
- Produce and socialise** clinical guidelines nationally
- Influence** decision-makers to prioritise health and wellbeing of tamariki and rangatahi
- Provide** whānau information for tamariki and rangatahi health and wellness
- Partner** with organisations and related sectors to improve child health outcomes
- Monitor data** to inform planning, management and measurement of outcomes

A Season of Change

The health system in Aotearoa is currently undergoing significant change to reduce inequity and ensure better access to healthcare to improve population outcomes. Clinical networks have been reflecting and are working to ensure alignment with the PSNZ Strategy to promote effective policies and practices to recognise and eliminate health inequities in Aotearoa and prioritise tamariki Māori.

The Child Development and Disability Network and the Cerebral Palsy Network are transitioning to the evolving Neurodevelopment Network, emphasising a collaborative approach to improving outcomes for tamariki and rangatahi. Denise Janes (Allied Health) and Dr Colette Muir are co-chairing the network. The transition supports the principle that there will be one point of contact for Whaikaha - Ministry of Disabled People to engage with clinical networks in relation to promoting service development for tamariki and rangatahi with disabilities. Dr Sue Stott will continue to Chair the cerebral palsy workstream.

In alignment with the PSNZ Strategy, the Cystic Fibrosis Network is transitioning into a broader Respiratory Network. Cystic Fibrosis will continue as a workstream. The evolving network will be co-chaired by Professor Cass Brynes and Dr David McNamara.

Clinical Reference Groups are being called Reference Groups to highlight the strengthening of membership to include experts from a range of areas. Some of whom may not be clinicians. For example, the Respiratory Network will have leadership from Te Aka Whai Ora in partnership to ensure work plans are prioritised to improve outcomes for Māori tamariki and rangatahi. The Reference Group will provide expertise and utilise the Te Tiriti Critical Analysis Tool to ensure work plans are prioritised and reflect whānau experience to drive system change and align with strategic direction. This is in response to the pressing health challenges faced by our communities, particularly those disproportionately affected by respiratory disease.



Paediatric Allergy Clinical Network

Shannon Brothers & Pauline Brown, Co-Chairs | Rosalie Hornung, Project Coordinator

Overview

Allergies affect over 20% of New Zealand's tamariki. This causes significant challenges for affected tamariki and whānau. Early diagnosis and appropriate clinical management support improved quality of life. In some severe cases, allergies trigger a life-threatening reaction known as anaphylaxis. Having a child with a food allergy is particularly challenging for whānau.

The network aims to promote evidence-based practice for the health workforce. This includes a focus on national quality improvement of service design to ensure access to care and resources is available.

The network achieves this by:

- Promoting accessible service delivery
- Socialising resources
- Developing guidelines
- Supporting workforce development.


The network has produced a range of guidelines, information, resources and training for health professionals.

Achievements

The clinical reference group has had a productive and busy year.

With an emphasis on contributing to allergy prevention, there have been a number of initiatives completed. We have taken stock of all web platforms that discuss allergy prevention, and there have been Facebook live events with the Plunket Digital Team and building of Well Child Tamariki Ora Provider connections.

A significant amount of work has been undertaken for the Allergy CRG Project Charter - Adrenaline Autoinjectors (AAI) in Schools. The main purpose of the charter is to collaborate with the Ministry of Education (MoE) and Ministry of Health (MoH) to advocate for tamariki and rangatahi to have access to an AAI at school and to advocate for training for school staff regarding the management of severe allergic reactions. Much of this work has been eased due to the funding of EpiPens in February this year. In conjunction with research collaborators, the data from the EpiPens in Schools survey was analysed and formed part of the Allergy CRG's commissioned report on 'A Review of AAI Practices in Schools.' This body of work evaluates the use of AAI and the management of anaphylaxis in schools in comparison to the context of the New Zealand environment.

Guidelines for health professionals have been updated and made available and published on the  Starship Clinical Network Webpage,

including the Soy Infant Formula information sheet, Calcium Needs for Children with Cow's Milk Allergy information for parents, and the Bee/Wasp Guideline. The Environmental Allergy Guideline is near completion as well.

The report on the findings of a stocktake of access to paediatric dietetic services for food allergies across Aotearoa has been completed and submitted to the MoH. This highlighted clear inequity in access to specialist dietetic support around the country. With the number of infants and children with allergies increasing, it is imperative that this is considered a high priority within any kind of health restructuring within Te Whatu Ora.

The network is additionally actively working with KidsHealth to develop whānau-centred resources in multiple formats to promote active participation in the development and implementation of management plans.

Network Priorities

Recognising and addressing the needs of children with allergies to ensure every child has access to services and the opportunity to flourish in health and wellbeing.

The next phases of the AAI in Schools work plan will focus on advocating for tamariki and rangatahi who require an AAI (e.g., EpiPen®) to have access to this device while at school or in a school environment, whether individual or general use device. In addition to collaborating with the MoE and MoH to advocate for consensus guidelines and minimum standards of training for school staff regarding the management of severe allergic reactions. Collaboration and understanding of the needs across both education and health sectors are required to identify solutions. This work is likely to be a focus for the 2023-24 work plan.

The allergy prevention workstream will continue to be a focus in 2023-2024, with a plan to develop an allergy prevention resource.

The network will additionally continue to work with KidsHealth, with an aim to review and adapt content to improve the usability of allergy resources and health information for whānau. A consumer review will also be undertaken in this phase.



Clinical Network for Child Protection

Russell Wills, Chair | Sandra Braithwaite, Project Coordinator

Overview

The Paediatric Society of New Zealand's Child Protection Clinical Network is a multidisciplinary network of nurses, social workers, allied health staff, doctors, managers and funders working and leading in child protection and domestic violence within Te Whatu Ora.

The Clinical Reference Group governs the network, meets regularly and is responsible for delivering on our annual plan commitments to Te Whatu Ora.

Achievements

This year, the network delivered parent and public information updates in our disciplines on the Starship and KidsHealth websites, and an annual meeting focused on cultural competency in child protection. We have begun a discussion on a bicultural partnership, starting with our study day on 7th November in Rotorua.

Network members are leaders in and active contributors to national programmes of work in child protection and domestic violence. This year, network members contributed to the reviews of the ACC-funded child and adolescent sexual assault services, the Gateway Programme, Power to Protect (shaken baby prevention), the Violence Intervention Programme, the National Child Protection Alert System, and the Oranga Tamariki Practice Framework Expert Advisory Group. Our members support the national child protection memorandum of understanding between Oranga Tamariki, Police and Health and are leading the local implementation of the new schedule 5 of the MOU ("Uplifts").

The network is also actively involved in developing and delivering face-to-face and online training for clinicians in child protection and the response to domestic violence. This year, online programmes were developed for the Violence Intervention Programme, intimate partner violence and child protection modules, and well-attended national training in child physical abuse and child sexual assault were delivered in Auckland by the team at Starship's Te Puaruruhau multi-agency child protection service.

Network priorities

The Child Protection Clinical Network's purpose is to improve the care of children experiencing abuse and neglect and adult victims of family violence, to support practitioners who are working in this challenging area of practice and to advocate for improved services for victims.

Tamariki and whānau Māori are over-represented in our services, so we are committed to a bicultural Te Tiriti o Waitangi partnership and implementation of modern Te Tiriti principles of active partnership, protection, choice, and equity of outcomes for Māori.

Next year, the Child Protection Clinical Network will continue the journey towards a bicultural partnership, learning lessons from this year's study day. This will include planning and delivering next year's study day, continuing to support national work programmes, and implementing the recommendations of the reviews above. There will be continued online and face-to-face teaching and promotion of improved services for those who experience abuse and neglect.



Clinical Network for Children and Young People with Diabetes

Jo McClintock, Chair | Sandra Braithwaite, Project Coordinator

Overview

Approximately 2,000 tamariki and whānau are affected by diabetes in Aotearoa and have the burden of diabetes care for most of their lives. The disparities in diabetes outcomes are predicted by ethnicity and socio-economic status, where those who are most deprived or are Māori or Pasifika are most at risk of developing short and long-term complications.

There are also regional differences in workforce, outcomes, and access to gold-standard therapies, which contribute to the disparity. In Aotearoa, access to new therapies often lags compared to similar Western health systems globally. Further, when they are made available, Māori and Pasifika are not accessing these in an equitable way.




The New Zealand Clinical Network for Children and Young People with Diabetes aims to improve the health and well-being of people and whānau affected by diabetes and specifically target inequities. This is done by providing clinical leadership and oversight to ensure a planned and consistent approach to diabetes services for tamariki across Aotearoa.

The aim of the network is to improve the care of tamariki with diabetes and support their whānau through clinical networking and the development of resources.

Achievements

We are grateful to Debbie Rawiri, Te Kaiwhakahaere Māori te Rōpū mate huka, for gifting the clinical network the following kupu: As kaitiaki (caregivers/guardians) of diabetes-related services, it is a collective responsibility to establish an environment that facilitates a pathway for people with diabetes to navigate te ao mate huka – the world of diabetes. We look forward to working with our Māori Director, Wane Wharerau, to support the network in developing a te reo Māori interpretation of the network name.

This kupu will be on all of our documentation moving forward:

- Editable  **2023 Diabetes In Schools Action and Management Plans for Whānau**
- Editable 2023  **School Camp Care Plans Developed for Whānau**
- Updated KidsHealth documents – NEW: Nutritional Management for T1D and T2D
- Practical Tools Developed for  **Transitioning Between Paediatric and Young Adult Services**
- Memorandum of Understanding with the New Zealand Society for the Study of Diabetes
- Ongoing relationship with Diabetes New Zealand
- Developing connections with international partners
- Initiated a peri-procedure guideline using a co-design and whānau-informed approach
- Started a review of the national Diabetic Ketoacidosis Guideline

- Hosted a professional development day in partnership with New Zealand Society for the Study of Diabetes (NZSSD)
- Supported the Paediatric Specialist Workforce Survey
- Membership of the reference group was developed to ensure Māori, Pasifika, and whānau voices are represented
- Terms of Reference updated to reflect Te Tiriti o Waitangi guidance to ensure equity in access to healthcare and health outcomes.

Additional information

Diabetes is a key focus for health reforms and is undergoing significant change at all levels – nationally, regionally, and locally. It is important that the clinical network remains involved and active at all of these levels to reduce inequities and ensure positive outcomes for all tamariki with diabetes in Aotearoa, as diabetes is with them and their whānau for life.



Network priorities

People: Nga Tāngata

Develop national mechanisms and tools that support and equip whānau to be informed and involved in their healthcare.

- KidsHealth documents reviewed
- School action management plans
- School camp plans
- Promote health workforce development and support to enable professionals to use evidence-based practice in a culturally safe framework
- DKA Guideline
- Perioperative Guideline

Partnerships and Connectiveness

Promote the clinical network as the expert advisory group in tamariki diabetes in Aotearoa. Providing leadership through developing partnerships and connections across health and education sectors.

- Relationships with diabetes organisations developed and maintained
- Contribution to the New Zealand Society for the Study of Diabetes (NZSSD)
- Workforce Document
- Contribution to the Diabetes National Action Plan
- Quarterly update to key stakeholders

Improving Practice

Development and implementation of quality improvement activities to improve equity of access to healthcare for tamariki and rangatahi with emphasis on Māori, Pasifika, and disabled communities.

- National logbook
- Education resources
- Transition resources

Sustainability

To develop the clinical networks and embed activities to ensure sustainability.


- Terms of reference
- Membership development
- Quarterly reports
- Annual workplan and report

Child and Youth Eczema Clinical Network - Te Rōpū Kiripai Hapori

Angela Craig, Chair | Rosalie Hornung, Project Coordinator

Overview

Eczema affects around 25% of tamariki in Aotearoa. It is a very common condition, yet it is poorly understood and managed by health professionals and whānau across the motu.

Te Rōpū Kiripai Hapori is the Child and Youth Clinical Network for Eczema. Our clinical reference group for this network is made up of a small number of passionate health professionals from primary care, community, secondary and tertiary paediatrics. We are keen to spread the word about managing and treating eczema effectively. There are lots of great  **resources on our network page**, in particular.

Achievements

The last year has seen lots of mahi improving the resources available to health professionals and extending education to our Well Child Tamariki Ora providers. We have worked collaboratively with the Starship Emergency Department team to develop a junior doctor friendly eczema guideline for acute flares, and the action plans from this are being used nationwide.

Extensive work has been completed keeping our health professional and whānau resources on the network page and the KidsHealth website up-to-date, accessible and relevant. QR codes on many of the action plans will help with links to more information.

Several of our members have fronted live chat sessions with Whānau Āwhina Plunket sessions for their consumers on eczema-related topics that have been recorded and are available for future viewing.

Activity has shifted towards developing a national education package for Well Child Tamariki Ora providers on eczema and its management. The hope is that by providing this workforce with clinically sound eczema knowledge, they can pass this on to whānau to better care for their pēpi and tamariki with this condition.

Network priorities

Equity of access to knowledge, resources, and appropriate treatment is still the network's biggest concern. Childhood eczema is a chronic condition that research shows significantly affects quality of life.

Eczema is best managed with appropriate whānau education and close community health and primary care input. Unfortunately, GPs are some of our most time-poor health professionals, so often eczema is only seen when acute, during short appointments, without routine follow-ups.

On the other hand, nurse-led clinics successfully manage these children well and empower whānau on this journey. These clinics are also successful with appropriate cultural support

and translated resources. However, current funding models don't prioritise nurse-led primary health clinics.

Hospital admissions for skin infections and related eczema flares are unacceptably high for our Māori and Pasifika tamariki. How we deliver education to support preventative models of care in the health system is an evolving process. It is a key priority area to help keep tamariki with eczema out of hospital and promote health and well-being.



Child and Youth Clinical Network for Gastroenterology Services

Cate Fraser-Irwin, Chair | Amy Andrews, Project Coordinator

Overview

Paediatric gastroenterology in Aotearoa continues to be a vulnerable service.

The NZCYCN for Gastroenterology Services Clinical Reference Group comprises of dedicated members representing multiple disciplines across several regions. The network aims to:

- Improve health outcomes for tamariki and whānau impacted by gastrointestinal conditions
- Address postcode inequities for whānau driven by the variance in access to specialty multi-disciplinary care
- Progress, educate and empower our health workforce to deliver local subspecialist care
- Develop whānau-centred clinical guidelines, pathways and resources in partnership with cross-sector key stakeholders
- Advocate for the needs of our tamariki and whānau at primary, secondary and tertiary levels and across relevant government organisations.

Achievements

Over the past year, the network has focused on projects within our new work plan and resolving historical work plan items. We have embraced new ways of working together and aimed to push the limits of what the network can achieve.

Of note, this year, the clinical network has:

1. Provided an opportunity for clinicians from all disciplines to learn, connect, and network via the first Inflammatory Bowel Disease (IBD) Education and Network Day held at Te Wao Nui, Wellington, on the 28th of July. The event was attended by over 50 clinicians from all over Aotearoa with an interest in IBD. This event was developed in partnership with PSNZ with the aim of providing a cost-neutral event and a facility for providing funding for clinicians without CME to attend.

PSNZ partnered with us to organise the event using a third-party event website, Eventbrite, as a platform for event information and registration. The event provided expert IBD multi-disciplinary presentations, case studies and networking. Preliminary feedback has been very positive, and clinicians are eager to engage and collaborate to provide positive outcomes for tamariki. There was a particular shared interest in the transition of tamariki with IBD, which will be a focus moving forward for the clinical network.

The network has achieved its objective from this activity and has moved from IBD writing

guidelines to empowering and educating our multidisciplinary workforce.

2. Published the New Zealand Conjoint Committee for Recognition of Training in Gastrointestinal Endoscopy – published June 2023 on the NZ Society of Gastroenterology website.
3. Developed and published the educational video resource **‘Use of swallowed Fluticasone for children with Eosinophilic Oesophagitis’** in collaboration with PSNZ and KidsHealth.
4. Commenced the research process of obtaining consumer feedback for the Starship Child Health non-biopsy diagnosis of coeliac disease and the Te Whatu Ora Northern Region coeliac disease pathway. The network aims to evaluate the current pathways and partnership with Coeliac NZ to advocate for a national rollout across regions.
5. Updated and published clinical guidelines and resources for gastrointestinal conditions such as biliary atresia.
6. Continued collaboration with the Royal Australasian College of Physicians (RACP) to progress the evidence-based EVOLVE statements.

Additional information

At the first IBD Education and Network Day previously mentioned, there was robust and enthusiastic discussion on the topic of transition and the absence of nationally agreed processes and mechanisms for transition. We would like to signal that this is an important point of discussion and merits collaboration across the wider PSNZ clinical networks.

Network Priorities

The core priorities for the network are closely aligned with our work plan and PSNZ strategy. We will aim to refine and incorporate Te Tiriti with guidance as the coming year progresses. The current core priorities for the network are:

1. To continue to improve the treatment and management of liver disease
2. To improve the diagnosis and management of coeliac disease (CD)
3. To improve the treatment and management of inflammatory bowel disease (IBD)
 - Develop and maintain IBD clinical network of clinicians for ongoing collaboration and education
 - Target key areas for development, including transition
 - Review of IBD education resources for adoption or adaptation
4. To ensure equitable access and provision of endoscopy services are in alignment with the formally agreed set of national standards
5. Continue to develop and strengthen child and whānau-centred education resources on a variety of platforms in partnership with key stakeholders and shared equitably across Aotearoa with specialist services and relevant organisations
6. Maintain clinical network infrastructure and sustainability: use of an active work plan that aligns with PSNZ strategy.

Paediatric Neurology Clinical Network

Rakesh Patel, Chair | Rebecca Berry, Project Coordinator


Overview

The network provides a voice for the 7.5 FTE paediatric neurologists in Aotearoa, along with nurse specialists and interested other secondary paediatricians. The forum allows NGO groups to have a say in the network.

The work within the network is provided by some hospital time, with the majority of work being done on a voluntary basis. We provide a service extending the length and breadth of Aotearoa, serving 1.25 million children.

Significant changes have occurred in the past year. Important changes in funding for the life-altering disease spinal muscular atrophy (SMA) has meant that individuals with this condition find improvement and are predicted to live longer. The delivery of these medications and measurement of outcomes is highly labour-intensive. However, there has not been any increase in clinical FTE to account for this. That being said, funding for this medication is a significant step forward.

Achievements

- The most significant achievement has been resuming work from before the COVID-19 lockdowns.
- During the national lockdowns, the network provided guidelines and made progress on significant work such as the 'Code Stroke' protocol. This in itself was a huge body of work.
- Revision of the  **Epilepsy Guidelines** to meet international standards - these have a nationwide reach.
- The network continues to support the Paediatric Epilepsy Training Programme to update paediatricians interested in epilepsy support to provide standardised care nationwide.
- Revision has gone into the Starship Headache Guideline to align with current practices internationally and nationwide.
- Progress is being made with a transition pathway from paediatrics to adult.

Te Tiriti o Waitangi and equity are key to the direction of the PSNZ Strategy. Future work will be required to consider models of care and resource requirements to improve outcomes for tamariki and rangatahi.

An area of focus is to commence Buccal Midazolam training updates that include documents in multiple languages, including te reo Māori.

Network priorities

This year's goals will focus on providing equitable access to the newly funded SMA treatments and utilising this substantial health investment to the best of our abilities.

The network will finalise the 'Code Stroke' protocol, continue the Buccal Midazolam training, and focus on a local Australia and New Zealand child neurology congress. We're also continuing our transition pathway and developing a webpage to make this information easily accessible nationwide.

As a group, we're continuing to identify service demands and limitations nationwide, looking at what is available in each area, how this can be optimised, and how we can provide support.



The Paediatric Palliative Care Network

Amanda Evans, Chair | Jo Truscott, Project Coordinator

Overview

The Paediatric Palliative Care (PPC) Network has a vision that all pēpi, tamariki, rangatahi and whānau in Aotearoa have access to palliative care that meets their needs.

The network aims to ensure the establishment of nationally equitable service with a focus on:

- Delivery of the PPC model of care to Te Whatu Ora, Te Aka Whai Ora and Whaikaha
- Ensuring integration and coordination for key stakeholders
- Meeting all current priorities, incorporating best evidence and up-to-date national and global information
- Recommending education development goals to build national capacity
- Recommending workforce development and implementation
- Linking current and future relevant work to the paediatric workforce.

Achievements

The network has expanded its membership and has had a change of Chair. This has brought a fresh start and a new drive to achieve our goals. We acknowledge those participants who have left, whose years of experience and dedication to PPC have been the foundations that our work builds on.

Our new members are enthusiastic, interdisciplinary, and representative from regions around Aotearoa. For the first time, we have Māori representation, which is essential as we know that Māori tamariki dying with palliative care needs are over-represented in our statistics. Additionally, Māori are likely to live in regions with no paediatric palliative care access. This will also be a huge asset to the network as we work towards incorporating Te Tiriti o Waitangi values, developing the Māori workforce, and partnering with communities to find solutions.

The network is committed to achieving equity and access to palliative care for tamariki, and we will be engaging with Te Whatu Ora to progress a national model of care.

The PPC monthly education continues to be a success and features national and international speakers. The audience includes paediatrics, allied health, schools, and hospice staff.

The network has started a database of members across Aotearoa and will utilise this to send bi-monthly newsletters to continue to raise awareness of PPC issues, education sessions, research, or opportunities.

Network priorities

Te Pae Tata Interim New Zealand Health Plan has included paediatric palliative care as a priority to be funded and implemented by 2025.

A model of care has been developed, and the network will be part of scoping and developing this model in partnership with Te Whatu Ora and Te Aka Whai Ora. We are looking forward to commencing this piece of work.

To achieve our goals across 2023 -2025, we have developed 4 different work streams:

1. **Equity of Access:** through supporting the delivery of a model of care (as above).
2. **Equity for Māori:** establishing gaps through research, working with communities to find solutions, focusing on increasing the Māori workforce and partnering with Hauora Māori Services.

3. **Raising Awareness:** through monthly education, newsletters, and bringing those who are working in this field together.
4. **Elevating the Voice of the Child:** by developing a youth advisory group in order for tamariki to continue to be front and centre.

Additional information

It is essential to the network that those working with tamariki with palliative care needs are emotionally and cognitively supported.

Members of the network have committed to keeping each other and the workforce in Aotearoa well so they can continue to do this tough work and do it in a way that they feel safe and supported. We do this because tamariki who require palliative care are precious, and we need our health professionals to stay well to care for them in the best way possible.

For clinicians reading this, if you have questions or concerns, or need to chat, please email us, and we will find a member of the network to reply and offer support. We are here for you, you are not alone -

✉ ppccn@paediatrics.org.nz



Newborn Clinical Network

Malcolm Battin, Chair | Claire Annan, Project Coordinator



Overview

The Newborn Clinical Network is a national multi-disciplinary group that supports clinicians working across primary, secondary and tertiary services to deliver high-quality, cost-effective and integrated newborn treatment programmes for babies and their whānau.

The aim of the network is to provide clinical leadership in the development and maintenance of a sustainable nationwide, clinical service for newborns as close to home as is practicable.

The network has a multi-prong approach with the appointment of a national, multi-disciplinary clinical reference group supported by clinical leaders from medical, nursing, and allied health professionals. The clinical reference group will provide advice on service and treatment issues to PSNZ, the NZCYCN Programme's Advisory Group and the Ministry of Health – Manatū Hauora.

Achievements

- Reviewing the clinical reference group's terms of reference alongside the PSNZ equity plan to ensure Te Tiriti and equity are kept at the forefront of the network's focus
- A new practice recommendation was completed for the 2-year follow-up of infants at high risk of developmental disability
- The network updated the  consensus statement for Screening for Retinopathy of Prematurity
-  New Zealand Clinical Network Practice Recommendation for LISA (Less invasive surfactant administration) / Minimal invasive surfactant therapy/MIST Practice Recommendation were published in April 2023
- Incorporating a new video into the red reflex screening assessment in newborns and infants consensus statement with very positive feedback and traffic on the Starship website (Feb 1,024 views, March 1,150 views, April 996 views).

Network priorities

- Developing more content for the newborn area on the KidsHealth website, to ensure up-to-date whānau information is available along with information that is easy to understand and follow
- Benchmarking Neonatal units across NZ/ ANZNN² data
- Producing an endorsement document from the clinical reference group to advocate FiCare within neonatal care around Aotearoa
- National cot status and need for review/ frame work paper to Te Whatu Ora for key considerations for neonatal care, including transitional care requirements
- Top 3 practice recommendations to review: Bundle of neonatal care at 23-24 weeks gestation, Skin care of neonates at 28 weeks gestation, and New Zealand Consensus Statement on the care of mother and baby(ies) at periviable gestations.

² ANZNN Australia New Zealand Neonatal Network

Additional information

In addition to the other activities, we have worked with tertiary NICU staff to identify opportunities that support education of our neonatal trainees across the country. Additionally, develop a group that can lead fellow education.

Finally, the clinical reference group has provided interdisciplinary collaboration in assessing and ultimately endorsing two documents. The first is a practice guideline on Small For Gestation, and the second is a consensus statement on Umbilical Cord Lactate.



Paediatric Sleep Medicine Clinical Network

Dawn Elder, Chair | Sandra Braithwaite, Project Coordinator

Overview

The Paediatric Sleep Medicine Clinical Network is a multidisciplinary group including clinicians and researchers. The network's clinical focus is on diagnosis, investigation and treatment of sleep disorders in tamariki and rangatahi.

Our research focuses on documenting the prevalence of disorders in Aotearoa, such as:

- Obstructive sleep apnoea (OSA)
- Hypoventilation requiring respiratory support
- Disorders of excess sleepiness, such as narcolepsy

Behavioural sleep disorders, such as sleep onset insomnia and sleep phase delay.



Achievements

This year has been a transition year. The network continues to be concerned about the state of clinical services for tamariki and rangatahi who have sleep disorders. We are also concerned that there are gaps in research information about the prevalence of sleep disorders in Aotearoa. Promotion and funding are areas we would like to address as we connect with Te Whatu Ora on the new healthcare system.

The network is currently building relationships between the three regional centres for tertiary sleep clinical care. We have started to develop a process of nationwide case reviews and referrals to provide alternative solutions for tamariki and rangatahi waiting for investigation.

On a practical side, the network has been working on the review of Visi-Download 2, the new software recommended for reporting

oximetry data. The aim will be to develop recommendations for a system that can be used around the motu so that it is easy to get second opinions about individual patient data.

We continue to value having representation from our paediatric ENT colleagues on the clinical reference group of the network. We have agreed that medical and surgical clinical services need to be considered together when reviewing clinical service provision for tamariki and rangatahi with sleep disorders such as obstructive sleep apnoea.

The network has also updated five KidsHealth documents related to sleep disorders. We have found that it has been efficient to do this online with the KidsHealth expert and a whānau voice available, as well as the clinical experts. This means we can provide accurate and expert information for whānau, translated into appropriate language for the public in a single online session.

Network priorities

The network is focused on the following priorities:

1. Paediatric sleep medicine clinical services are under-resourced in Aotearoa. We cannot keep pace with clinical demand, and wait lists for both assessment and diagnosis have become unacceptably long. Also, despite the increasing technological improvements in CPAP and BiPAP treatments for a range of types of sleep-disordered breathing, many paediatric and adolescent patients with a clinical need for these treatments do not have access to them. For those with access to these treatments, there needs to be more clinical resources to provide ongoing surveillance of their progress to ensure optimal use of the therapy.
2. The network is also concerned about barriers to timely ENT surgery for children with OSA with adenoidal and/or tonsillar hypertrophy.
3. Development is underway for a nationally connected hub and paediatric sleep medicine service in Aotearoa with three tertiary sites: Christchurch, Wellington and Auckland, with Auckland having an additional role in managing patients on long-term ventilation.
4. As most specialist SMOs in this clinical area in Aotearoa are now trained as respiratory and sleep medicine specialists, promotion for these tertiary services across the motu would be best undertaken in alignment with the Paediatric Respiratory Clinical Network.
5. The network's promotion for clinical service provision must be based on current and accurate epidemiological and prevalence data from our local population. The network's sleep research workstream will focus on this area to develop appropriate projects to address gaps in our information about paediatric sleep disorders and their management in Aotearoa.
6. Although the above priorities are the network's primary focus, there will be ongoing collaboration with KidsHealth to ensure information related to paediatric sleep disorders is relevant and current. The network is planning ongoing education opportunities to engage colleagues on paediatric sleep medicine topics.

KidsHealth

Delivering child health messaging for parents and whānau

Paediatric Society NZ - Te Kāhui Mātai Arotamariki o Aotearoa oversees the development, governance and maintenance of high-quality digital child health content. The Society is uniquely placed to develop and endorse nationally consistent messaging on tamariki and rangatahi health and wellness for parents and whānau via the:

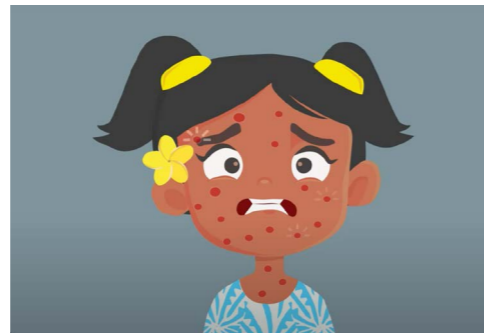
- KidsHealth Programme (with funding from Te Whatu Ora - Health New Zealand)
- 650+ multidisciplinary members and subject matter experts
- Child and Youth Clinical Networks and Special Interest Groups
- Partnerships and relationships, especially developing relationships with Māori organisations whose mahi is to improve outcomes for tamariki and rangatahi
- PSNZ/KidsHealth partnership with Healthify (previously Health Navigator) and HealthInfo Waitaha/Canterbury - sharing content and working towards a national digital health content hub.

Reducing health literacy demands faced by parents and whānau

KidsHealth is increasingly using multiformat content to communicate messaging, reduce health literacy demands faced by parents and whānau, and enhance user engagement.

Recent examples

The development of animations to share messaging on whooping cough and measles immunisation.



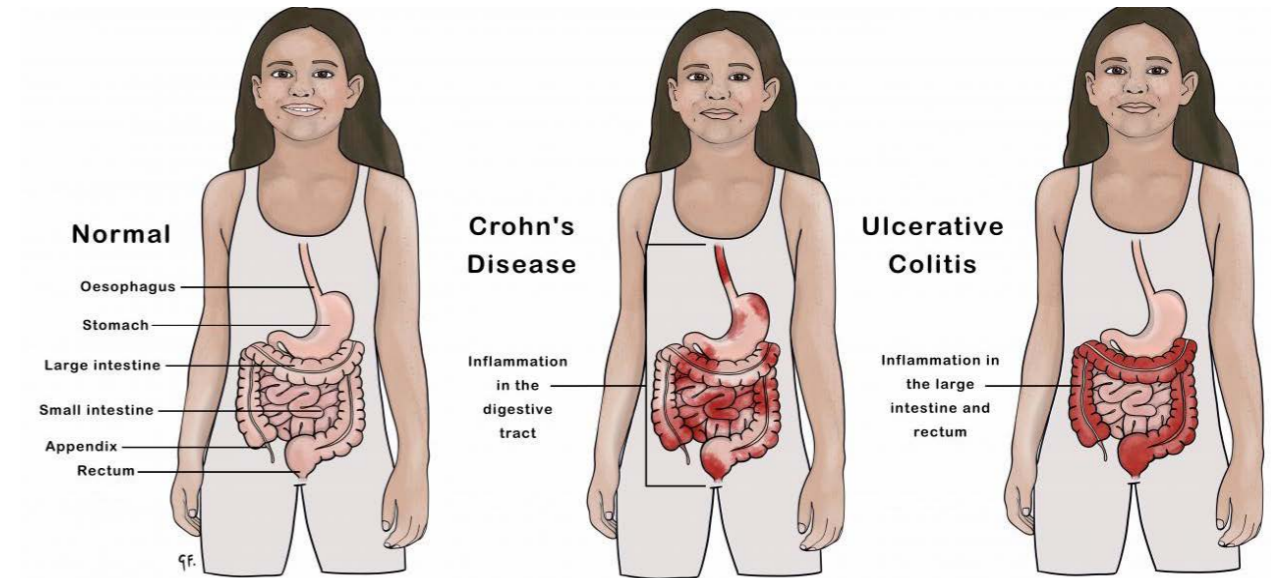
Animation on measles immunisation

<https://kidshealth.org.nz/measles-immunisation>



Animation on whooping cough immunisation

<https://kidshealth.org.nz/whooping-cough-immunisation>



Illustrations to help build understanding about a condition. For example, an inflammatory bowel disease illustration. It shows how the digestive tract is affected by Crohn's disease and ulcerative colitis.

<https://kidshealth.org.nz/inflammatory-bowel-disease>

Protect tamariki for life - immunise
Start immunising pēpi the day they turn 6 weeks old

Meningococcal B disease
[QR Code]

Whooping cough
[QR Code]

Measles
[QR Code]

Find out about all the immunisations pēpi and tamariki can have - watch some videos

[QR Code]

KidsHealth is New Zealand's trusted voice on children's health. Endorsed by The Paediatric Society of New Zealand | Te Kāhui Mātai Arotamariki o Aotearoa

KidsHealth
www.kidshealth.org.nz

Scan the QR code with your phone to view website content

KidsHealth
www.kidshealth.org.nz NZ's trusted voice on children's health

Check ideas for keeping tamariki and rangatahi healthy

Find out what to do when your child is sick

Read about children's emotional and mental wellbeing

Learn about common conditions

Watch videos about children's health

Accurate & reliable information for NZ parents & whānau about the health & wellbeing of tamariki & rangatahi. Endorsed by The Paediatric Society of New Zealand | Te Kāhui Mātai Arotamariki o Aotearoa

Scan the QR code with your phone to go to the KidsHealth website

QR code posters to provide easy access to specific KidsHealth content

Value of the KidsHealth Programme

Clinical governance

Content developed & approved by the Paediatric Society of NZ

Hundreds of hours contributed free by PSNZ membership & Clinical Networks



National content hub collaboration

KidsHealth's content is shared on other websites - Healthify & HealthInfo

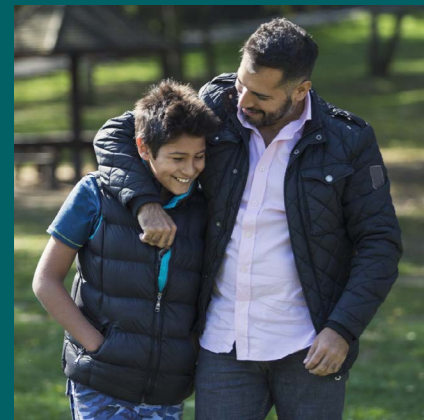
Increases content reach

Improves information consistency

Avoids duplication

Reduces clinical review time

Multiformat content to support user engagement



User feedback

"As a kiwi this is the most helpful, straightforward, well laid out and clear, concise health site I've been on. Thank you" (NZ parent of 9 year old with croup)

User feedback

"Awesome resources for supporting after disasters - do you have anything in Te Reo as I have lots of Kura Kaupapa Māori and Kohanga Reo asking. many thanks" (Education Manager, New Zealand)

User feedback

"tena tatou, ... your guidelines for coping with 'teenagers testing boundaries/ inappropriate anger etc. is the best so far ... so thanks, go well, naku noa na" ("NZRN the last 44 years", NZ)

KidsHealth
www.kidshealth.org.nz

Accurate & reliable information for NZ parents & whānau about the health & wellbeing of tamariki & rangatahi in Aotearoa

Our People

Governance Group

Role	Name	Professional role(s)/area of expertise	Location
Member	Bridget Farrant	Senior Lecturer / Adolescent Physician	Tāmaki Makaurau
Member	Cameron Grant	Professor / General Paediatrician	Tāmaki Makaurau
Member	Christine McIntosh	GP Liaison Child Health	Tāmaki Makaurau
Member	Daniel Gotz	Te Aka Whai Ora	Te Tai Tokerau
Member	Karen Magrath	Nurse / Principal Clinical Advisor - Plunket	Te Whanganui a Tara
Member	Loren Mooney	Paediatric Nurse Practitioner / Public Health Nurse Practitioner	Whanganui
Member	Mary Roberts	Nurse, General Manager - Moana Research	Tāmaki Makaurau
Member	Megan Bryant	Consumer Representative	Kaiapoi
President PSNZ	Mike Shepherd	Paediatrician, Interim District Director	Te Toka Tumai
Chair	Nicola Austin	Neonatologist	Ōtautahi
President-elect	Owen Sinclair	General Paediatrician	Waitematā
Co-opted Member	Rachael Hetaraka-Gotz	Nurse, Acting Manager: Well Child Tamariki Ora, Child and Community Group	Te Tai Tokerau
Co-opted Member	Timothy Jelleyman	Community Paediatrician / Child Health Advisor MOH	Waitematā
Member	Toriana Hunt	Kaimahi Hauora Māori	Ōtautahi
In attendance PSNZ	Jontel Kiwi Kiwi	Programme Manager Te Tiriti o Waitangi and Equity	Te Tai Tokerau
In attendance PSNZ	Karyn Sanson	Support Manager NZCYCN	Tauranga
In attendance Te Whatu Ora	Leonie McCormack	Manager, Family & Community Health / Child & Community Health	Te Whanganui a Tara
In attendance PSNZ	Pam Henry	Programme Director - PSNZ	Tāmaki Makaurau
In attendance PSNZ	Wane Wharerau	Māori Director Te Tiriti o Waitangi and Equity	Tāmaki Makaurau





Ehara taku toa
I te toa takitaki,
He toa takitini

My strength is not as
an individual but as
a collective