



“Tamariki in Aotearoa flourish in health and wellness”

Newsletter of the Governance Group for New Zealand Child and Youth Clinical Network | Issue 1 - 2023

Tēnā Koutou Katoa

It's my pleasure to introduce the March CYNet 2023.

In December 2022 I replaced Dawn Elder as chair of the NZCYCN Governance Group. A special thanks to Dawn for her leadership during her tenure, as well as her activity in networks and PSNZ over her career.

I'm a neonatal paediatrician of 30 years now, and have worked in Ōtepoti and Ōtautahi. I have been very fortunate to have pursued a busy career and see our two tamariki flourish. But this was only possible with whānau support.

When I started there was one female paediatrician in Dunedin (the above mentioned Dawn Elder) I took over from her. Since then there have been increasing numbers in training as registrars and as paediatricians in general and all subspecialties. This is something that resonated on International Woman's Day on 8th March. Unfortunately the proportion of Māori paediatricians has been slower to rise.

Leadership roles are important to prepare for. There are many more training opportunities now than when I started. Our professional bases for example: RACP, Nurses Aotearoa, and our hospitals all have great online webinars and courses now. If there is one positive from COVID is that we have become more proficient in making the most out of digital opportunities.

In this CYNet we outline the ToolBox project which has identified the myriad of resources and sites where information may be found or we can use in the future to showcase or disseminate our mahi and outputs.

The release of the updated and new guidelines on Palliative Care are a demonstration of a significant output for the network program.

The trial Hub in Wellington for early detection of Cerebral Palsy follows on from the CP network pathway developed in 2022. There are more challenges for pēpi than CP and a holistic approach is needed.

In late 2022 PSNZ contracted Wane Wharerau as Māori Director and Renee Smith-Apanui as Program Manager Te Tiriti o Waitangi and Equity. The Governance Group, Network Leads and Project Coordinators celebrated their appointment formally at a face to face meeting in December.

This day then involved workshops and good korero on how we as a Society and the networks can follow the 2021 Strategy of PSNZ to meet our Te Tiriti obligations and address the many health equity issues faced by tamariki and rangitahi in Aotearoa/New Zealand.

Renee's workplan is being finalised and starting with the clinical leads and project coordinators she is preparing zoom meetings and webinars to bring into focus the ways we can adapt our workplans. You will hear more about this in the next 6 - 12 months.

It is a forward thinking direction for PSNZ and one we should be proud to be part of.

Feel free to share your feedback either directly to the admin emails or on Discourse for PSNZ members. We are eager to hear your ideas and meet your needs as we work hard in our busy workplaces.



Nicola Austin
Chair
NZCYCN Governance Group

ToolBox Project

In 2022 the NZCYCN conducted a project to gather information on the a range of digital options available to disseminate child health information to health professionals. The aim was to provide the Clinical Networks with a toolbox for use when they have information to disseminate, either nationally or to specific target audiences. The information gathered is now available for use by the CNs.

The toolbox provides information about the variety of organisations that deliver child health information to health professionals across sectors; including Māori, Pasifika, primary health, rural, university educational settings, secondary, tertiary services and disability.

Some examples of the information gathered include:

1. Goodfellow - produce a fortnightly newsletter that is sent to around 35,000 recipients, webinars that reach around 450 people, and podcasts that average 1200 downloads per month. There are associated costs for webinars to be delivered
2. Australian and New Zealand Association for Health Professional Educators (ANZHPE) - run online PD sessions once a month with a reach of around 700
3. NZ Breastfeeding Alliance - produce a monthly newsletter that goes to around 500 people
4. Royal College of GPs - produce weekly e-newsletters, monthly newsletters, and webinars that reach around 5,500 GPs including regional and rural
5. Turiki Healthcare (provide whānau-based health, wellness and social services to people in South Auckland) - produce a monthly newsletter that is sent to around 250 staff and has a Facebook page with around 11,000 followers.

Initially we plan to support Clinical Networks to utilise the tool. Therefore a process for discussing available digital options has been developed as follows:

- Clinical Network requests a work plan planning meeting inviting the Operational Support Manager and the Communications Manager – currently Karyn Sanson and Ally Clelland
- Discuss the purpose of the information being developed; Consider target for the delivery of information and consider possible options for dissemination
- Refer to the toolbox
- Investigate further options if a specific target audience is required i.e. neurologists, physiotherapists etc
- Report back options to the Clinical Network who add this to their workplan
- Feedback from the Clinical Networks will be sought regarding the usefulness of the information provided.

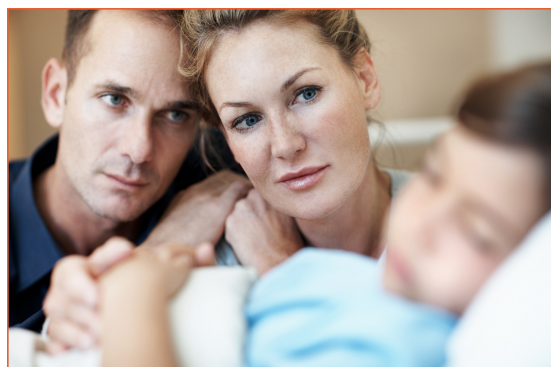
The toolbox is a living document. It will be updated and kept current by the Administration and Communications Team. There will be a review of usefulness, so that networks have the opportunity to provide feedback and ensure it is useful.

New Guidelines Developed for Palliative End of Life Care

In 2019 The Paediatric Society of New Zealand commissioned a suite of clinical guidelines for paediatric end of life care in New Zealand.

The project had two aims - to update existing Paediatric Palliative Care in New Zealand: Clinical Guidelines of End-of-Life Care (2015), and to create new components for end-of-life care.

The new guidelines were finalised at the end of 2022 and are available on the [Starship Clinical Guidance page](#).



The project was conducted by an independent consultant Dr Elizabeth Bennett and Paediatric Palliative Care Specialist at Starship Hospital Dr Emily Chang. Reviews were completed by the Starship Palliative Care Team and the Palliative Care Clinical Reference Group. Each guideline was reviewed by international experts in paediatric palliative care.

Dr Chang says, “The project was conducted over 12 months in three consecutive phases. Phase 1 involved the development of the project plan, completion of a literature review to identify high quality source guidelines, and review of existing project development methodology and tools. Phase 2 consisted of the selection of guidelines for inclusion. Phase 3 comprised extraction of relevant material from source guidelines to updating existing guidelines and develop new guidelines.”

Each guideline was written using material from carefully selected international guidelines in paediatric palliative care. The source guidelines were tested methodically for quality using the AGREE II instrument and included if sufficient standards were met.

The result of the project is a suite of clinical guidelines which are presented as 18 stand-alone

documents. The guidelines address: sharing significant news; planning care; pain assessment and management; symptom management; and psychosocial, spiritual and cultural care.

Dr Chang says, “The 2015 guidelines that addressed care planning comprised: Sharing Significant News; and Planning Care. Our source guidelines provided better and more specific information, enabling more specific new guidelines. These include Sharing Significant News about End of Life, Planning End of Life Care, Location of End of Life Care, Allowing Natural Death, Organ and Tissue Donation, and Dispute Resolution.”

They are intended to be used by secondary medical, nursing and allied health providers who care for babies, children and young people at the end of life and are freely available on the internet. The 2015 guidelines were widely accessed in New Zealand, Australia and sometimes unexpected places such as Sweden, Denmark, India and Poland.

Both the 2015 and the 2022 set of guidelines were developed with the financial support of the Ministry of Health and PSNZ through the NZCYCN program.

New hub to support early diagnosis of Cerebral Palsy in high-risk infants in Aotearoa New Zealand



An early detection hub to improve access to early Cerebral Palsy (CP) detection assessments has been set up in Wellington. The Hub is part of the PĒPI ARC study (Partnering Early to Provide for Infants at Risk of Cerebral Palsy) investigating the feasibility of implementing the New Zealand (NZ) Best Practice Recommendation for Early Detection of Cerebral Palsy, Monitoring and Intervention.

The PĒPI ARC hub champions a whānau centred model of care, created around the notion of A Family (of clinicians) caring for a Family (whānau). It incorporates a multidisciplinary face-to-face clinic and telehealth to enable flexible access to CP assessments for pēpi and their whānau, and support for clinicians.

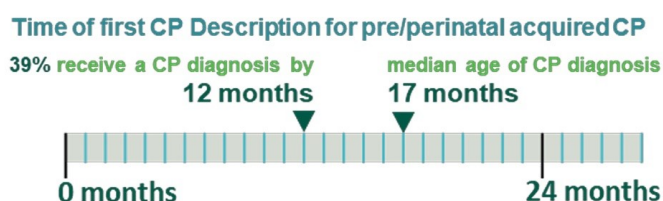
PĒPI ARC is exploring if implementing the best practice recommendations through the Hub model can decrease inequity in accessing CP assessments for high-risk babies admitted to the Wellington NICU early in life, no matter if they live in Wellington or another region. The aim is to diagnose infants with CP as early as possible, enabling pathways to earlier targeted interventions at the age when the brain has the most neuroplastic potential, as well as surveillance of medical complications and emotional and practical support for whānau.

CP is the most common motor disability in childhood. In NZ it is estimated a baby with CP is born every three days. CP is caused by abnormal development of the brain, or damage to the developing brain most often occurring during pregnancy, birth or soon after birth. Babies born very premature, very small, or who are very unwell early in life and requiring admission to a neonatal intensive care unit (NICU) have a higher risk of neurodevelopmental impairment, including CP.

Infants with detectable risk factors can now be diagnosed with CP or identified as being at 'high-risk of CP', as early as 3 months of age (corrected for prematurity), through the combination of three evidence-based diagnostic tools: General Movements Assessments (GMA - assessment of babies' movements), Hammersmith Infants Neurological Examination (HINE - standardised neurological assessment), and brain imaging.

The use of these tools to make an accurate and early diagnosis of CP were outlined in an international best-evidence clinical practise guideline in 2017. Based on these guidelines, the New Zealand Cerebral Palsy Network has developed Best Practice Recommendations for NZ, to make it easier for clinicians and therapists to implement these tools, interpret the results, and confidently make a diagnosis.

However, a large gap exists between the evidence-based practice recommendations and the clinical reality in NZ. Data from the NZ CP register show that less than 40% of children with CP are diagnosed before 12 months of age, with median age at diagnosis being 17 months. At the same time, data from the NZ CaPTuRE study showed that parents and whānau often suspect that their child to have CP, or a CP like conditions, 6 to 12 months before they are given a diagnosis. This delay contributes to an increase in parental stress and anxiety, distrust in medical health professional, dissatisfaction and frustration with the diagnostic process and delay in accessing targeted interventions and support.



*The New Zealand Cerebral Palsy Register Report 2022,
Te Whatu Ora, Te Toka Tumai, Auckland, New Zealand (2022)*

During the planning and preparation phase, the PĒPI ARC team engaged with stakeholders to develop the different components of the hub. These included local and regional whānau with experience of neonatal follow-up, CP assessments and lived experience of CP, and regional paediatricians, therapists, and Child Developmental Services. The study has now moved into its implementation phase and enrolment started in Wellington NICU on 1/3/23, coinciding with the opening of the hub.

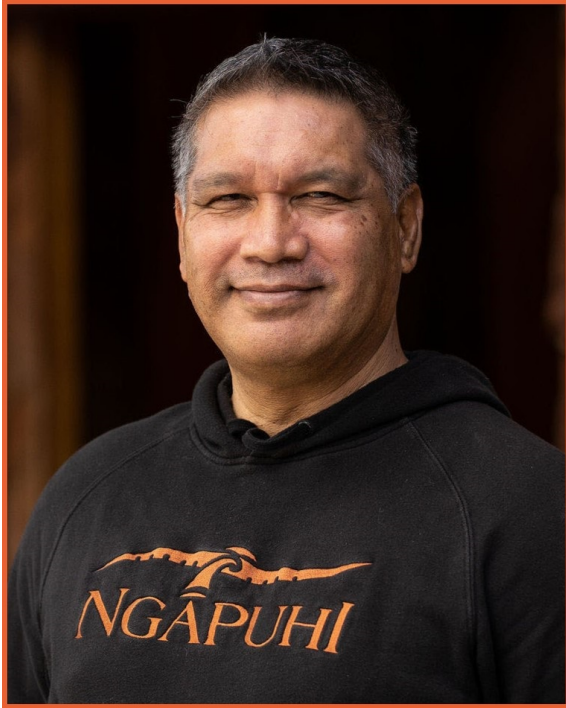
PĒPI ARC is being funded by research grants from the Australian Cerebral Palsy Alliance, Health Research Council of New Zealand and a research scholarship from the New Zealand Federation of Women's Institutes.

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Introducing our new Executive members: Wane Wharerau and Renee Smith-Apanui



Wane Wharerau, Māori Director



*Renee Smith-Apanui, Programme Manager
Te Tiriti o Waitangi and Equity*

In early December the Paediatric Society held a mihi whakatau to welcome our new Māori Director, Wane Wharerau (Ngāpuhi), and Programme Manager Te Tiriti o Waitangi and Equity, Renee Smith-Apanui (Te Rarawa, Ngāpuhi, Waikato-Tainui) as well as President Elect, Owen Sinclair (Te Rarawa).

So what's their background?

Mr Wharerau just finished as Iwi Liaison Officer with New Zealand Police plus holding several governance positions within the Ngāpuhi Group and with other national iwi organisations.

Mrs Smith-Apanui comes from a project management background in Māori health outcomes sitting on multiple boards and advisory groups championing Te Tiriti and Equity, and has held senior roles at several organisations including Rautaki Consultancy and TOA Architects.

But what will these two roles actually do for the Society?

PSNZ President Mike Shepherd says the Māori Director role will partner with the senior leadership team to help drive change and contribute to all key decisions.

“Wane will partner with the Executive team in decision making, connect the society with iwi, enhance equity from Māori perspective, and ensure Māori world view is incorporated in all of our work.”

Wane says, “I am looking forward to working with the Executive team to ensure their key objective of health equity is aligned with Māori outcomes. The key to this is improved relationships and awareness at governance level. Māori are a young flourishing population with the potential to influence the future of Aotearoa in a positive way provided they have strong leadership.”

Renee will initially be working with the Clinical Networks to help embed Te Tiriti and Equity in line with the strategic direction of PSNZ. This will involve understanding the current knowledge level of the clinical networks and working to develop resources and workshops to assist in progressing this in to the future.

Renee says, “I am passionate about ensuring outcomes for tamariki and their whānau and excited to help achieve this alongside PSNZ through the further embedding of Te Tiriti and Equity.”

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