

CYN^et



Health of our children: Wealth of our nation

Newsletter of the Advisory Group for New Zealand Child and Youth Clinical Networks Issue 1 - 2020



From the Chair

This year has been a busy period for the New Zealand Child and Youth Clinical Network programme (NZCYCN). This publication captures activities from some of the Clinical Networks (CNs) and I'd note the release of the programme's July 2018 – June 2019 Annual Report to the Ministry of

Health (MoH) will soon be available on the Paediatric Society of New Zealand's (PSNZ) web site. Please check this out in the near future, meantime it is my pleasure to provide this update.

After considerable discussion with the MoH two new CNs have been approved. This newsletter profiles more on these developments. The new CNs are the Cerebral Palsy and the Child Development and Disability CNs. The Cerebral Palsy CN had its first face to face meeting early November and the Child Development and Disability CN has a meeting scheduled for early March 2020. A lot of work has been done in preparation and both groups are pleased to be able to move their aims along.

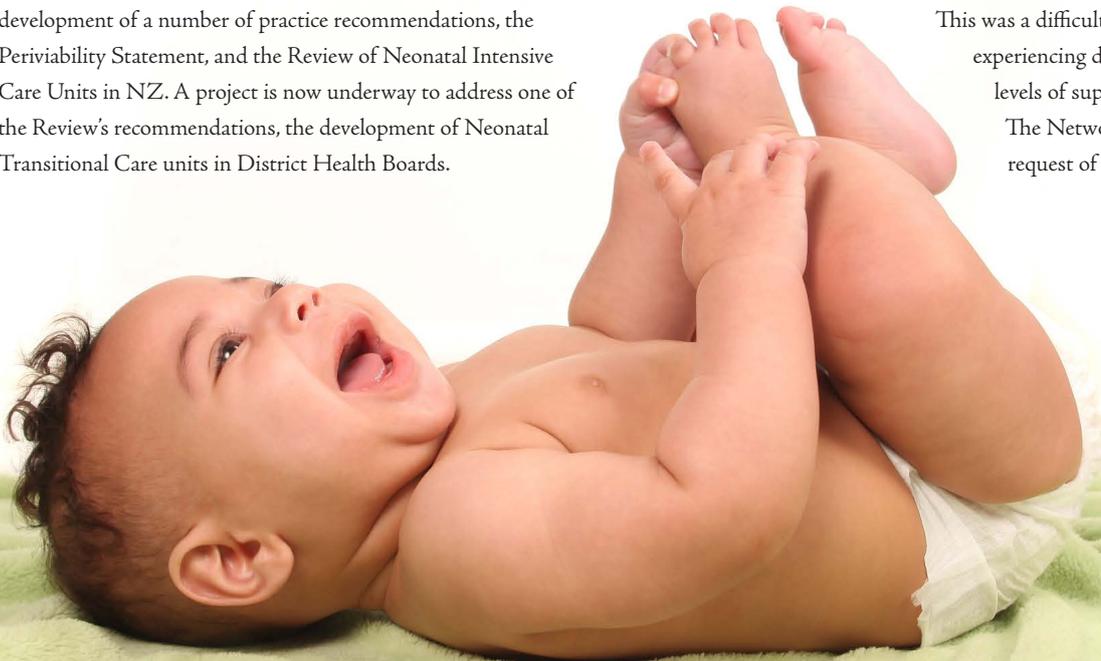
The Newborn CN has had an extremely busy year with the development of a number of practice recommendations, the Periviability Statement, and the Review of Neonatal Intensive Care Units in NZ. A project is now underway to address one of the Review's recommendations, the development of Neonatal Transitional Care units in District Health Boards.

The Child Protection Clinical Network continues to promote many activities including a very successful Special Interest workshop at PSNZ Annual Scientific meeting for which 120 people were registered this year. Other activities included engagement and support for the Child Protection Alert System in DHBs, and maintenance of the 3 Memorandums of Understandings held with related bodies (e.g. Police, DHBs, Oranga Tamariki). This network has an important role supporting the very skilled specialists and many multidisciplinary health professionals in this sector. More on the above two CNs further in this publication.

The Starship web site has undergone a significant upgrade. This site is the home of the NZCYCN programme resources, and changes have been designed to enhance access for professionals to this information. The upgrade also allows us to use Google analytics to track trends and access. In October alone over 4,600 hits were made. More on this change in this publication. A process to support scheduled reviews of all CNs resources is in place, and a number of resources have been reviewed this year.

The Tube Feeding CN was established in 2015 with well-defined goals regarding tube feeding and weaning to oral feeding.

This was a difficult area with many families experiencing dissatisfaction with the levels of support that they could access. The Network was established at the request of the Ministry in response to a



petition from parents and others requesting action in the area. The Network has worked very effectively to develop a comprehensive set of practice recommendations now available on the Starship website. In line with the intention at the time the Network was established, the CN will move to being a PSNZ Special Interest Group (SIG) in 2020 and the NZCYCN Advisory Group thanks all concerned for their hard work and wish them well in their future activities.

Acknowledgments and farewells:

Welcome to the Advisory Group;

We welcome Professor Cameron Grant to the group. Cameron's expertise is in clinical practice, teaching and research and I know he brings these valuable attributes to the team.

Sadly, we say farewell to Professor Dawn Elder, who has been the chair of the Child Protection CN for a number of years. Dawn leaves the CN in very good heart and our sincere thanks and best wishes are extended to her in her future endeavours.

To Associate Professor Nicola Austin, who has chaired the Newborn CN since its 2010 inception and under her leadership the CNs' achievements are remarkable. However, it is great to know Nicola's leadership expertise is not lost as she is taking on the role

of the PSNZ President. Thank you Nicola for your commitment to the CN and we look forward to you continuing to be part of the Advisory Group.

Sadly, the Advisory Group says farewell to Trish Hastie, Child Health Consumer representative, CDHB and Toriana Hunt, Kaiwhakamahere Hauroa Tamariki, Child Health Services (CDHB). Both members will be very much missed.

Last, but not certainly least, our sincere thanks and farewell to Dr Pat Tuohy who in his role as Chief Advisor Child and Youth Health, MoH has championed the NZCYCN Programme from its earliest days to the successful programme it has become. While Pat is now retired, he holds a special place in the programme's development and subsequent achievements.

On behalf of the Advisory Group I thank all those who are leaving for their commitment and very positive contribution to the governance of the NZCYCN .

Richard Aickin

Chair,

NZCYCN Clinical Advisory Group.

The Cerebral Palsy Clinical Network

The Cerebral Palsy Clinical Network (the Network) held its inaugural meeting in November. The Network's interim chair is Professor Susan Stott and the Network will work in partnership with the Cerebral Palsy Society. A wide range of multidisciplinary clinicians from around the country expressed an interest to be involved and attendance at the November meeting was enthusiastic and very positive.

The deliverables of the Network include:

- Develop and promote best practice recommendations and resources for health professionals that support early diagnosis, early intervention, and effective early management of Cerebral Palsy
- Incorporate children and young peoples' voices to the Network's planning and subsequent activities
- Design and develop improved transition of young people with Cerebral Palsy from paediatrics into adult health services
- Establish a workforce education and development programme
- Support the development of a sustainable pathway for the NZ Cerebral Palsy Register so that data from the Register can feed into other work streams
- Create comprehensive understanding of key aspects of specific therapies for example but not limited to Selective Dorsal Rhizotomy and intensive therapies amongst District Health Boards and related Ministries
- Promote active participation in all aspects of life for people with Cerebral Palsy
- Develop a system for the monitoring and auditing of services to inform continuous quality improvement of Cerebral Palsy care
- Identify and liaise with national and international bodies with relevance to childhood Cerebral Palsy.

The Network would welcome people interested in participating in any of the workstreams to contact us and, (the Network) will work very closely with the Child Development and Disability Clinical Network.

Child Development and Disability Clinical Network

In August this year the NZCYCN approved funding for the Child Development and Disability Clinical Network. (CD&D CN). This was fortunate timing with the Ministry of Health announcement of increased funding for Child Development Services and increased political focus on Child and Youth Well-being with the release of the Child and Youth Well-being strategy.

While the network is in its infancy and is still to establish a Clinical Reference Group, the interim co- chairs were able to meet with key stakeholders in the Ministry of Health to discuss options for on-going liaison between the Ministry and the Clinical Network, particularly in regard to the work being undertaken around the Child Development Services, but also ensuring alignment of the CD&DCN with MOH priorities.

The Network has also been in contact with the Northland, Midland and Southern Regional Alliances establishing reciprocal relationships around disseminating of information, establishing a National Platform for sharing of information and initiatives and a collaborative National approach.

The Network is also working closely with the Cerebral Palsy Clinical Network and will next year merge to become one overarching Clinical Network, with many shared goals and visions.

With a focus on equity it is an important time for those working in Child Development and Disability. The Clinical Network will

be a national multi-disciplinary health network that will support clinicians working across community, primary, secondary and tertiary services to deliver high quality, cost effective and integrated child development and disability services for children, youth and their whanau. The aim of the Child Development and Disability (CD&D) Clinical Network (CN) is to provide clinical leadership in the development and maintenance of a nation-wide, clinical service(s) for children and youth up to 18 years of age.

Aims of the Network are:

- foster a culture of a nationally coordinated child and youth development and disability continuum of care
- develop a model of care
- establish a workforce education and development programme
- develop a system for the monitoring and auditing of services to inform continuous quality improvement
- identify and liaise with national and international bodies with relevance to childhood child development and disability services

The first meeting for the Clinical Reference Group will be early March 2020, prior to the Paediatric Update in Auckland. The Network is currently seeking interested MDT clinicians keen to helping to establish this Network.



Newborn Clinical Network update

This Newborn Clinical Network has had a very busy 12 month period as a number of resources have been completed along with the successful completion of a review of Neonatal services. The following is a snapshot of some of this Network's activities.

An excellent Less Invasive Surfactant administration (LISA / MIST) guideline and video have been developed and are now on the website. Web site analytics show this is a very popular resource and in only one month was viewed 176 times <https://www.starship.org.nz/guidelines/practice-recommendation-for-lisa-mist/>



In 2018 a review of Neonatal Intensive Care Unit Capacity and Resourcing in NZ was commissioned by the Ministry of Health (MoH), support by District Health Boards (DHBs) with the Newborn Network taking the lead. The review followed previous reviews of 2004 and 2008 and since the Network commenced in 2013 neonatal and special care unit capacity issues have been on the Workplan. A three month project to profile the continuing issues was undertaken by Malatest International early 2019 and completed March 2019. Extensive consultation and feedback from all neonatal services in NZ resulted in a Neonatal Intensive Care Unit Capacity and Resourcing in NZ Report and the Report included a number of recommendations. The MoH and DHB Chief Executives have agreed to support progress on these recommendations and the Transitional Care Implementation Plan project is now underway. Stakeholders in the project include key DHB clinicians and managers, MoH representatives and the project is chaired by this Network. The aim of the Transitional Care programme is to keep more babies with their mothers on

the postnatal ward and reduce some of the pressure in the NICU/SCBU. All DHBs and the MoH are engaged in the development of an Implementation Plan for Transitional Care and the timeline for completion of the fixed term project is before the end of 2019. More information on this development can be sought through DHB's services. The other recommendations in the Neonatal Intensive Care Unit Capacity and Resourcing in NZ Report are to look at the resource constraints and cot capacity as well as an improved dashboard to monitor activity and identify available cots.

After extensive national consultation with a wide section of interested specialities a Periviability Statement has been completed and is now on the PSNZ and the NZCYCN Newborn Clinical Network's websites <https://www.starship.org.nz/guidelines/new-zealand-consensus-statement-on-the-care-of-mother-and-baby-ies-at/>

Network members convened a group including our Paediatrician colleagues and NZCOM, to address the management of babies who lose excessive weight after birth. These babies are cared for in NICU/SCBU's and Childrens wards with severe hypernatraemic dehydration. <https://media.starship.org.nz/guidelines-relating-to-weight-loss-in-newborns/guidelines-relating-to-excessive-weight-loss.pdf>

The newborn encephalopathy practice recommendation has also been updated and can be viewed at <https://www.starship.org.nz/guidelines/neonatal-encephalopathy-consensus-statement-from-the-newborn-clinical/>

Several of the network are also members of the Newborn Encephalopathy Taskforce that is supported by ACC. The work programme includes; (i) Developing a Newborn observation chart and Newborn Early Warning score; (ii) Cord lactate assessment; (iii) Electronic wellbeing assessment with fetal monitoring and, (iv) Growth Assessment Protocol GAP, the assessment of intrauterine growth.

Ongoing work continues with reviewing the follow-up needs of babies who come through NICU and future plans include (i) progressing work on a neonatal formulary within NZULM; (ii) care of babies with Trisomy 18 and 13; (iii) and consent; (iv) working collaboratively with the new Child Development and Disability Network.

Ongoing liaison with the Kidshealth to ensure information on that site is relevant and current.

*Newborn Clinical Network
Associate Professor Nicola Austin, Clinical Leader*

Child Protection CN Update

The Child Protection Clinical Network was one of the first New Zealand Child and Youth Clinical Networks established in 2010 with Dr Patrick Kelly as initial Clinical Lead. Miranda Ritchie was the next Clinical Lead and I took over from Miranda in 2016. As clinical Leads we work with the Clinical Reference Group (CRG) and together aim to provide leadership within the health sector to improve outcomes for infants, children and youth exposed to, and at risk of, child abuse and neglect.

The Network was initially set up at the request of the Ministry of Health (MOH) to support and enhance child protection services in the sector. One of the key objectives for the network is to be identified as an expert resource for child protection in health. There is considerable expertise in the CRG and members are invited to participate in aspects of national planning regarding family violence and child protection services and the membership continues to lobby associated bodies to promote the depth of expertise available. As Clinical Lead I sit on the Oranga Tamariki Practice Frameworks Advisory Group and that has provided the Network with an important opportunity to promote the key role of health professional in child protection services.

Activities over the last 12 months have included providing a submission on the Child Wellbeing Strategy; offering feedback to Oranga Tamariki—Ministry for Children on their Information Sharing Guidance and supporting the Paediatric Society of NZ to send a letter of support in regard to the Choudray statement on abusive head trauma. The CPCN website has been updated and updates have also been made to information contained on the KidsHealth site.

Work continues regarding the update of the Memorandum of Understanding (and associated schedules) between Health (DHBs), Oranga Tamariki and the Police. The ongoing legislation changes that could impact on these documents has resulted in the work on this being delayed. The current documents remain binding; they are available on the CPCN website [https://www.](https://www.starship.org.nz/health-professionals/clinical-network-for-child-protection/)

[starship.org.nz/health-professionals/clinical-network-for-child-protection/](https://www.starship.org.nz/health-professionals/clinical-network-for-child-protection/)

The Network also provides clinical leadership of the Child Protection Alerts System (CPAS). Patrick Kelly and his team continue with the research projects that are reviewing the way in which this system is working. Phase three of the national evaluation is progressing well. In 2019 the CPCN endorsed the *CPAS Frequently Asked Questions* resource that provides a ready-reference document for DHBs. Thanks to Miranda Ritchie for her work on this.

Provision of workforce development for the sector is another deliverable and the annual Child Protection satellite day remains a key action to support this. Since 2010, this annual meeting has attracted more than 100 attendees per session. The programme formulae balances national updates with practical, practice-based information and plenty of time for discussion. A successful Special Interest Group Workshop was held in Albany on Tuesday 19 November., the theme was *Opening Gateways - Overcoming Barriers*.

A significant piece of work undertaken by our group was a questionnaire sent to NZ Paediatricians asking about their involvement in Child Protection work. The results are now published and the next piece of work is to try and address some of the issues that were documented <https://onlinelibrary.wiley.com/doi/abs/10.1111/jpc.14504>.

While the CPCN has been operational for nearly ten years, the network cannot exit until child abuse and neglect is no longer a problem for Tamariki in Aotearoa or until child protection services in health work perfectly and seamlessly in association with Oranga Tamariki and the NZ Police. Until that time, we recognise the invaluable work that is occurring through the collective efforts of those contributing to enhanced safety and wellbeing for children and young people.

Professor Dawn Elder, CPCN Clinical Leader



Clinical Guidelines on website support paediatric clinicians nationwide

The new Starship website was released in July 2019 with the result that measuring usage with google analytics is now quite different with the new structure.

Page views have decreased overall as more people access the guideline/clinical information directly from the search bar on the main page. <https://www.starship.org.nz/health-professionals>

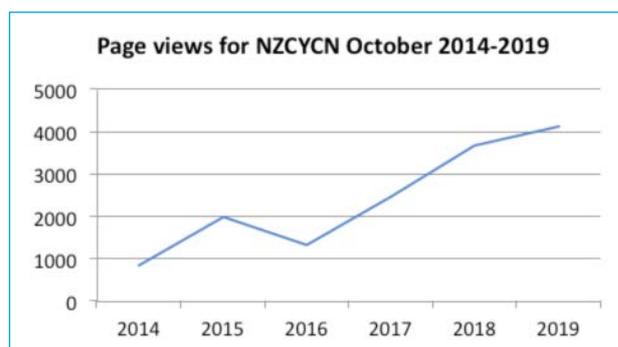
The average bounce rate for the clinical guidelines (the measure of whether people exit the site via the page they have chosen) over the past month is around 83%. This suggests people are finding the clinical information they want quickly without having to search through a range of pages.

Visits to the Clinical Networks web page, October 2019	
Network	Number of visits
Diabetes Clinical Network	833
Gastroenterology Clinical Network	554
Sleep Clinical Network	142
Neurology Clinical Network	752
Newborn Clinical Network	297
Child Protection Clinical Network	15
Allergy Clinical Network	293
Eczema Clinical Network	636
Cystic Fibrosis Clinical Network	468
Palliative Care Clinical Network	568
Tube Feeding Clinical Network	101
Overall total for October	4605

The average time on page for the clinical guidelines is highest with around four minutes per page view. The table below left is an overview of web page views/downloads of Clinical Networks (CNs) for Oct. 2019

The graph below tracks the five year trend from initial development (e.g. six CNs) through to October 2019 and 12 CNs. The CNs are the only website group that show increased levels for this period in 2019 compared to previous years. This may reflect the impact of the newer more efficient search engine in the new website and combining network guidelines with all the other guidelines, rather than separately under the CNs.

In general, total website users for October 2019 have increased by 47% from October 2018, with a 55% increase in new users.



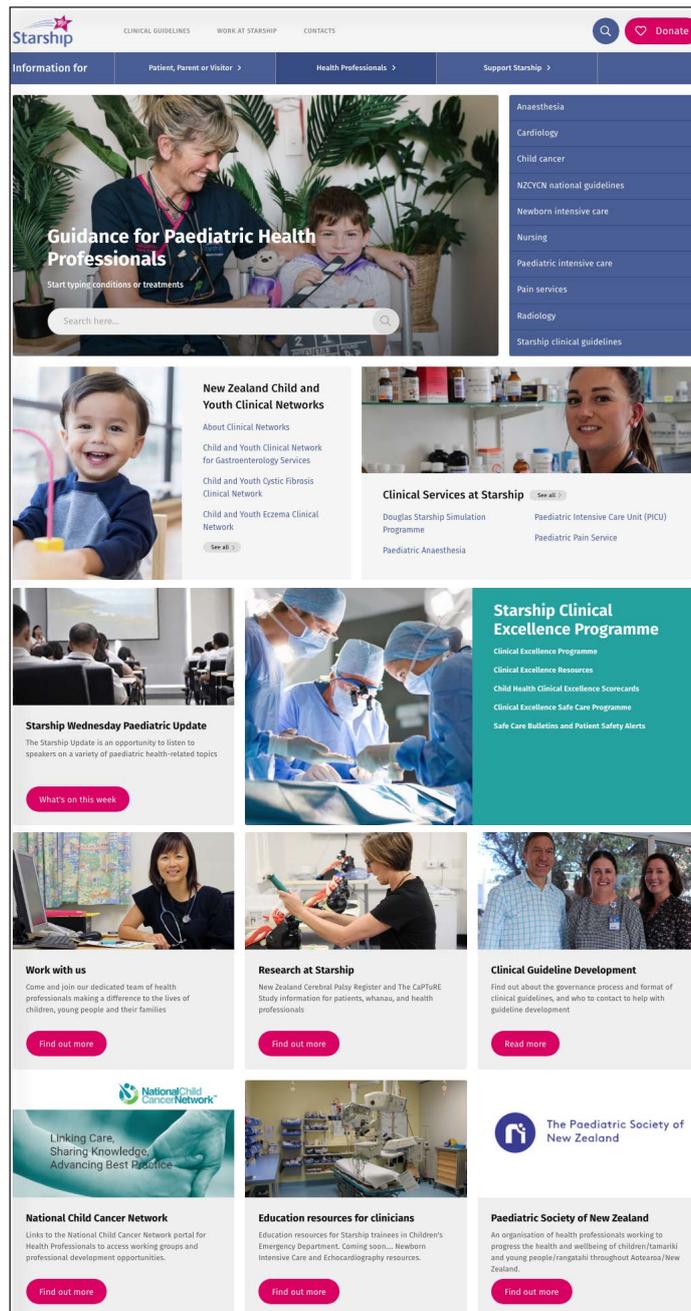
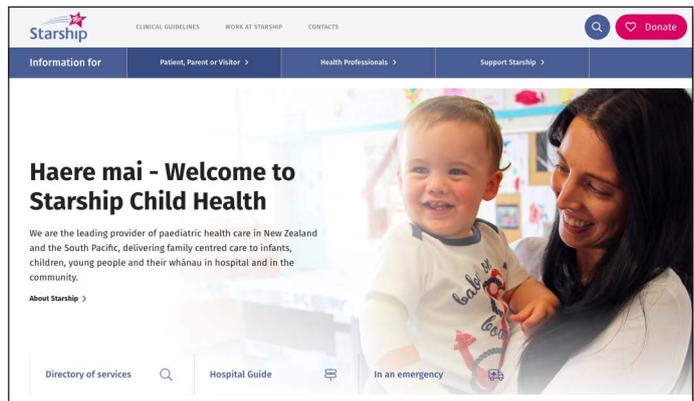
Total visits to all Clinical Network pages for October 2019

Highest usage by New Zealand region

Auckland
Wellington
Christchurch
Tauranga
Hamilton

Highest usage by international city

Sydney
Kuala Lumpur
London
Johannesburg
Semarang



Most popular information sought in October 2019

Diabetic Ketoacidosis Guideline
Idiopathic Intracranial Hypertension
Biliary atresia
Outpatient/primary care management of eczema
Eczema clinical network

Feedback and trends

Feedback welcomed, none received this month

NB. Access in any month may reflect clinical updates, public health matters that could reflect public/ clinical interest, conference presentations.

Susan Cato-Symonds, Website Director



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YOUR CONTRIBUTIONS We welcome thoughts, contributions and articles and notices of upcoming events. Please email the editor, Lauren Young on lauren@laurenyoung.co.nz