



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



Paediatric Society of New Zealand

A summary of the development, implementation and achievements of

The New Zealand Child and Youth Clinical Network Programme

February 2021

Since 23 March 2020, the impact of the Covid-19 pandemic has significantly changed the ability of clinicians to invest time in this programme and subsequently advance the aims of each clinical network. Additionally, the NZ national pandemic management plans have impacted on face-to-face meetings. Until further notice all communications will be via Zoom or phone links.

Collated by
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Abbreviations and Glossary

CN	Clinical Network: Term used to describe each subspecialty clinical network, which has been established after a business case has been received, and approved by the NZCYN Governance Group and Ministry of Health
CRG	Clinical Reference Group: A multidisciplinary, expert clinical group, established to agree the terms of reference, deliverables, workplans for each CN and report on results
FAQ	Frequently asked questions
DHBs	District Health Boards. The 20 boards developed from the New Zealand Public Health and Disability Act 2000
GP	General Practice / primary health care services
Gov Gp	The Governance Group for the NZCYCN programme. Name changed from Advisory Group
HQSC	The Health Quality and Safety Commission works with clinicians, providers and consumers to improve health and disability support services.
MoH	The Ministry of Health leads New Zealand's health and disability system and has overall responsibility for the management and development of that system
MoA	Memorandum of Agreement: Is a cooperative agreement written between parties to cooperatively work together on an agreed upon project or meet an agreed upon objective.
MoU	Memorandum of Understanding: Formal agreement between key stakeholders and or organisations whose practice links with and or supports the NZCYCN programme
NZ	New Zealand
NZCOM	New Zealand College of Midwives
NZCYCN	The New Zealand Child and Youth Clinical Network Programme; a quality improvement initiative
NZCYES	The New Zealand Child and Youth Epidemiology Service http://dnmeds.otago.ac.nz/departments/womens/paediatrics/research/nzcyes/dhb.html
NGO	Non-Government organisation. Primary and community care health organisations
PSNZ	The Paediatric Society of New Zealand https://www.paediatrics.org.nz/
TOR	Terms of Reference: Defines how the group will function, the scope of practice / accountability including the core aims / objectives and responsibilities of the team

Introduction

Why Clinical Networks?¹

- To strengthen clinical leadership nationally and locally
- Provides incentives that support structured, quality improvement activities
- To develop and sustain specialty, multi-disciplinary teams, to work effectively and support the transfer of care across/ between horizontal and vertical continuums of care
- To seek new forms of association / integration between institutions, often based on care pathways or joint assessments
- Belief that a networked approach can help share risks, reduce costs to member institutions and/ or improve health outcomes
- Facilitate family centred care models, based on cooperation and provide more specialist care, or care support by specialists through generalist Paediatrics, closer to home
- Effective and efficient platform on which to build workforce capacity that include early intervention and primary care elements
- Supports development of multi-disciplinary teams at all levels
- Endeavours to utilise technology in terms of communication and to monitor outcomes
- Attempts to remove perverse incentives and promote best health outcomes

Clinical networks are a quality improvement tool for change in health service delivery². A brief overview of some of quality improvement activities of each of the networks is profiled below and on the website <https://www.starship.org.nz/health-professionals/about-clinical-networks>.

New Zealand Child and Youth Clinical Network Programme (NZCYCN)

The Paediatric Society of New Zealand (PSNZ) has a contract with the Ministry of Health (MoH) to development and implement a strategic approach to national clinical networks for some child and youth health services. The MoH – PSNZ contract has been renewed several times and the current contracted period is through to June 2022.

The contract requires the appointment of a Governance Group³ to provide governance and support to the contract's operations. MoH approve the appointment of a Governance Group Chair and membership of the Group is representative of a range of multidisciplinary professional leaders from the sector. Geographical and urban / rural memberships is reflected in Governance Group appointments.

A number of documents inform and support the (national) clinical network development. These include but are not limited to

- NZ Government's *'Better Public Service (BPS) Targets'*⁴. In particular targets 2 and 3.
- *Ministry of Health's (2016) Health Strategy – Future Directions and its partner document Road Map of Actions*.
- HFA and PSNZ 1998 Report, *'Through the Eyes of a Child'* and subsequent MoH (2010) update on *Specialist Health and Disability Service for Children: A High-Level Review*
- MOH 1998 *Child Health Strategy*
- Cropper et al *'Making Sense of Strategic Networks'*⁵
- The Evaluation Report⁶ *on the Development and Implementation of the New Zealand Child and Youth Clinical Network Programme (2017)*
- *New Zealand Child and Youth Epidemiology Service's National and District Health Board reports*

NZCYCN Programme development process

A management process has been developed to identify and implement each subspecialty clinical network. This includes terms of reference, appointment of leaders / chairs⁷, clinical reference groups (CRGs) work plans, key performance indicators and reporting processes. All networks have now developed individual 3-year Strategic Plans.

1 Reference NHS (1999) – Scottish Executive Guidance. 12 Core Principles of MCN

2 Spencer A, Ewing C, Cropper S. Making sense of strategic clinical networks.

ADC Online First, published on July 25, 2013 as 10.1136/archdischild-2013-303976

³ Title changed from Advisory Group to Governance Group effective April 2020 as agreed by the Governance Group members and MoH representatives

4 <http://www.health.govt.nz/publication/delivering-better-public-services-good-start-life>

5 <http://adc.bmj.com/content/98/11/843>

6 The full report can be viewed at <http://www.paediatrics.org.nz/>

⁷ The original term for a CN's leadership role was 'Clinical Lead', over time some CNs have prefer the term 'Chair' In this document the term Lead will be used.

Publications

A bi-annual newsletter, *CYNet*, provides updates on network activities and introduces new clinical networks. The publication also includes links to each Network's web page. The *CYNet* publication(s) can be viewed on the networks web site NZCYCN website (above) and at [CYNet Newsletters & Presidents' Messages - The Paediatric Society of New Zealand](#).

Annual Reports to the Ministry of Health can be viewed at [NZ Child and Youth Clinical Network - The Paediatric Society of New Zealand](#).

Paediatric Society of New Zealand <http://www.paediatrics.org.nz/>

The Paediatric Society of New Zealand (PSNZ) is a multi-disciplinary organisation that links all DHBs and other childcare agencies. The Society can link initiatives through its

- 630+ memberships
- A wide range of horizontal and vertical subspecialist/specialist networks; 25 Special Interest Groups
- PSNZ web site that supports extensive information sharing
- Discussions supported mainly via Zoom s
- Support requests for representation on various committees/organisations, e.g. Ministry of Health, Pharmac, media requests for information, professional development matters

PSNZ achievements include the support and/or development of

- NZ Paediatric Surveillance Unit
- NZ Telepaediatric Service, the major provider of telemedicine in NZ (renamed Telemedicine)
- NZ Child & Youth Epidemiology Service
<http://dnmeds.otago.ac.nz/departments/womens/paediatrics/research/nzcyes/index.html>
- Development of a comprehensive range of Clinical Guidelines
- Parent Information website <http://kidshealth.org.nz/>

Overview of developments and or issues / concerns in child health

- Progress on
 - Nationally structured services
 - Well Child Tamariki Ora national services
 - Child & Youth Mortality Review Groups
 - Some national (MoH supported) services
 - Violence Intervention Programme
 - National Child Protection Alert System
 - Range of Oranga Tamariki programme with associated MoUs / MoAs
 - Serious with variable areas of fragility
 - Difficulties in sustaining some District Health Boards (DHBs) secondary services, especially those with small volumes and increasing complexity of care
 - The challenges of ongoing capacity and capability within the sector along with the increasing demands of highly specialised services at all levels of care
 - High variability in national respite services for families who have a child with a developmental and or a disability
 - The challenges of what is tertiary care and how to define, e.g.
 - Continued challenges in defining levels of care between sector, e.g. secondary and tertiary and how to manage these tensions in the varied locations
 - 'Tertiarity' is a result of several factors, e.g. complexity, severity of condition, age of child. A continuum of care is required to consistently provide support
 - Elements of 'fair and efficient' service delivery is not funded e.g. telephone, email and written consultation, literature research etc.
- Primary Care
The range of primary care services. This includes general practice, community services and Non-Government Organisations (NGOs). Being able to provide all services with updates and support for the increasing number of best practice information &/or guidelines being developed, is an ongoing challenge.
NB. All services now impacted by Covid-19.

Overview of New Zealand Clinical Networks at February 2021

The following is a 'snapshot' of achievement and further information on the established Clinical Networks (CNs) can be viewed on each CN's webpage.

Child Protection (late 2010) www.starship.org.nz/childprotectnetwork

Initially embedded in the work of PSNZ CP Special Interest Group (SIG), now a formal clinical network. Clinical leader, Facilitator and Clinical Reference Group (CRG) established. Work plan and achievements include:

- CRG is operational and terms of reference, work plan and key performance indicators agreed.
- Memorandum of Understanding (MoU) between DHBs, Child Youth and Family and Police: All DHBs have signed the MoU; the 1st schedule provides a guideline for the management of neglect of medical care; the 2nd schedule provides guidance on the management of children exposed to clandestine laboratories; the 3rd schedule provides guidance for the neglect of medical care; the 4th schedule is a joint standard operation procedure for children and young persons in clandestine laboratories and a 5th schedule for Securing Safety and Wellbeing of Newborns ('uplifts') is currently under development with two CRG members attending related meetings. The MOU and Schedules have a scheduled review date to ensure currency with changes to legislation and/or related operational requirements.
- The findings of the survey about child protection services available in all DHBs was presented at the CP SIG Satellite day in November 2017 and was published in 2019
- The findings from a questionnaire sent to Paediatricians regarding the challenges of practicing Child Protection was published in 2019.
- Operational management of the National Child Protection Alert System (NCPAS) was contracted to a provider in January 2020. There is a Memorandum of Understanding between the contractor and PSNZ for the CN to provide clinical leadership for the programme. Two CRG members are Senior Medical Advisors to the NCPAS and are key contacts for the contractor. This programme meets the Minister's Statement of Intent to DHBs and also requires biennial reviews of the system in all DHBs. A Frequently Asked Questions (FAQ) resource was finalised in April 2019 to provide considered and consistent advice. This resource has been made available to DHBs
- A national resource kit has been developed and provided to DHBs to support the development of Maternity Care, Wellbeing and Child Protection Groups in DHBs
- Supporting the implementation of the Children's Action Plan as relevant in contracted sectors
- Mindful of the need to be a key stakeholder in the implementation of the legislation regarding the Oranga Tamariki Ora / Vulnerable Childrens' programmes. Horizontal links established with key stakeholders.
- CRG members attend meetings related to child safety including a Practice Frameworks External Advisory Group and Health Services for young people in residential placements.
- Integrated workforce development with Violence Intervention Programme, e.g. shared workshops at the annual PSNZ Scientific Meeting. Due to Covid-19, the regular training programme was cancelled 2020 and a workforce development workstream is scoping the development of webinars
- Content on the NZCYCN website has been reviewed and updated on the KidsHealth website
- Power to Protect Program. Separate contract, but integrates with this CN
- Three midwifery leaders (including one Māori) are CRG members and a representative of the DHB National Child Health Managers Group now attends some CRG meetings

Diabetes (2011) www.starship.org.nz/diabetesnetwork

Clinical leader, Facilitator and CRG established. Work plan and achievements include:

- Virtual Diabetes register (VDR) developed in partnership with MoH. The register is for children with diabetes < 15 years, starting 2011
- A workforce survey has been undertaken by the Australasian Paediatric Endocrine Group the results of which have recently been published by a team that includes network members. The survey was redone and the results published in 2019. Currently, such surveys represent the only mechanism for updating workforce capacity and capability
- A clinical guideline for the management of Diabetes Ketoacidosis (DKA) has been updated. A Surgery protocol is in development and a Type 2 protocol is being investigated
- The 2016 survey of key stakeholders explored the transition from paediatric to adult diabetes. A major theme was the need for consistent support from the education sector and good support from clinicians was noted. A Consensus Statement on 'transition' to adult services has been developed incorporating the findings from the survey. The statement and a toolkit have been loaded on the CN's website
- Have developed NZQA medical certificate templates for both type 1 and type 2 diabetes mellitus treated with insulin to be used to support 'special assessment condition' applications for students with diabetes
- A network of health professionals who work with older adolescents with diabetes (15-24 years) is steadily progressing

⁸ Neels A, Tuohy P, Elder D for the Child Protection Clinical network. Training and confidence in undertaking child protection work as reported by New Zealand Paediatricians. J Paediatric Child Health 2019 May 29. [Epub ahead of print] <https://onlinelibrary.wiley.com/doi/abs/10.1111/jpc.14504>

⁹ Children and adolescents with type 1 diabetes in Australasia: An online survey of model of care, workforce and outcomes. Martin de Bock, Timothy W Jones, Jan Fairchild, Fran Mouat, Craig Jefferies. Journal of paediatrics and child health 55 (1), 82-86, 2019

- Diabetes in School Action and Management Plans and Exams & Diabetes are updated each year and loaded on the CN's website ready for the school year. These resources have been redeveloped into a distinctly New Zealand-branded document with improved usability
- Diabetes camp guidelines have been reviewed and revised and are now available on the website along with a report on a survey conducted about school camps. A follow-on survey of school camps and trips will be the focus of the CN's 2021 consumer survey
- A MoU with the Aotearoa College of Diabetes Nurses has been maintained since July 2015. Collaborative working relationships are in place to develop and share resources
- A paediatric focused meeting aligned with the NZSSD annual scientific meeting held May 2019, Victoria, Australia. The Australian group have shared some of their nursing/ school resources, these are now available on the NZCYCN / Diabetes CN's website and are maintained by the CN
- A survey of paediatricians and paediatric endocrinologists on insulin regimens used/facilities available at new diagnosis of diabetes has been completed as part of a large Australasian study. A manuscript based on the work was published in the Journal of Paediatric and Child Health in July 2017 entitled Insulin regimens for newly diagnosed children with type 1 diabetes mellitus in Australia and New Zealand: A survey of current practice
- A successful Paediatric Diabetes Study Day was held in May 2017
- A module-based patient information package (newly diagnosed education pathway) used in Adelaide has been updated and revised for use in New Zealand
- Glucose monitoring resourced developed and launched at NZSSD. It is loaded on the CN's website and a link to it is loaded on the KidsHealth website. CRG members are involved in ongoing research using continuous glucose monitoring and pump technology
- Continue to review and update diabetes related resources on the KidsHealth website. Also advice resources regarding children with diabetes and Covid-19 were developed and shared on KidsHealth
- A consumer survey looking at students with diabetes attending school trips and overnights was completed with the report soon to be available on the website. The report highlights the variation between schools regarding support available and/or accessed by families. A follow-on survey of clinicians is being conducted to identify where the gaps are occurring and this will inform future work
- The CN endorsed the published APEG guidelines for the management of type 2 diabetes in children and adolescents and a link to these is now loaded on the website
- Multiple collaborative research studies are occurring across the network
- A MOU with Diabetes New Zealand is under development
- Transition resources are currently under review
- Organising a webinar using the themes and content from the cancelled (due to Covid-19) 2020 combined CN & Diabetes Dietitians Diabetes professional development day.

Eczema (2012) www.starship.org.nz/eczemanetwork

The CRG was originally established with leadership shared between a Medical and a Nursing representative. The CRG's leadership is now shared between a primary care GP and a secondary care Paediatrician. Work plan and achievements include:

- Model of care developed and loaded on the website. It is regularly reviewed and revised as needed. Model of Care case studies have been compiled and an article drafted for review and possible publication
- Contribution to Well Child Tamariki Ora health book update
- Teaching/education includes presentations to regional PHN update; rural GP conference, GP registrars, support for RN education days by Pharmac and other organisations. Also organised an Eczema Nurses Study Day which was held in November 2018
- Video developed for KidsHealth on bathing and application of ointments/ creams. Very good feedback on this resource and this valuable resource is currently being updated. The English audio has been completed and translations in Te Reo, Samoan and Tongan are in progress
- Horizontal networking with Midland Child Health Action Group who have identified 'eczema' as a work stream to improve child health
- 19 DHBs have an identified contact person through which information and resource sharing can be channeled
- The CN's resources are reviewed and revised on a scheduled bases
- A pictorial handout has been developed and is loaded on the website, reviewed and revised regularly
- A Pharmac Study Day about introduction of foods for children at risk of allergy involving the Eczema and Allergy CN Chairs held in June 2017 and was repeated in 2018.
- A case study by the CN was published in the March 2017 CYNNet <https://www.paediatrics.org.nz/resources/cynet-newsletters-presidents-message/show/904>
- Due to numerous relevant articles and research findings, there has been regular communication with the wider network. Feedback has been positive and has prompted communication from members including

clinical questions or enquiries about resources to the CN clinical leads. These enquiries are useful to reinforce best practice or to identify resources or support needed. Often these enquiries support what the CRG has already identified as needed, such as the pictorial handout presently being finalized. Additionally, the network has had enquiries from clinicians wanting to join the mailing list indicating this information is being disseminated by our members

- The CRG now includes representation from Plunket who are providing advice on the development and distribution of resources for Well Child Tamariki Ora providers
- With support from Plunket, progressed Mythbusters/FAQs information and links for health professionals for the CN and KidsHealth websites. Once final, will determine context and type of resource needed to support Well Child providers (e.g. online information, handouts for families, training for nurses). Eczema information for health professionals on Health Navigator has been reviewed and updated
- Have reviewed and discussed preliminary report on HealthPathways eczema content
- Plan developed to establish and use HealthPathways links for communicating practice recommendations and resource
- A 'Nurses Survey on Eczema Education' has been drafted and is anticipated to be distributed in early February 2021. The distribution list continues to be developed

Palliative Care (2012) www.starship.org.nz/palliativecarenetwork

Clinical Lead and CRG established. In February 2019, leadership of the CRG transitioned from a doctor to a Nurse Practitioner (NP). Work plan and achievements include:

- MoU with Hospice NZ is reviewed and revised per specified timeline
- Monthly video conference education programme continues with more than ten sites for each forum. Recordings are made and loaded on the website when clinically appropriate to do so. Feedback is positive and the programme is also being used by rural sector RNs. A survey was undertaken in 2017, very positive feedback received
- Survey of Paediatric Palliative Care 'End-of-life' (EoL) Care Clinical Guidelines was completed at the end of 2016 and review of resources in 2018. Website analytics demonstrate that the guidelines are well utilised and other feedback is positive. A new contract was agreed August 2019 to update the EoL guidelines, some will be replaced, some updated and new ones developed. The guidelines are in the final stages of review and anticipated to be available via the web in early 2021
- Continued efforts to establish and retain links with MoH adult Palliative Care services and regional groups
- A successful international 'Train the Trainer' two-day education programme was supported by the network in 2017. The overall aim of the 'Train the Trainer' programme was to provide a practical and evidence-based approach as to how to teach paediatric palliative care. Feedback indicates this result was well met.
- Ongoing brief updates with the Newborn and Neurology CNs to establish horizontal links with a focus on common conditions/interests between CNs
- A MOU developed and maintained with Royal Childrens' Hospital Melbourne to share resources
- A consumer survey developed in Australia is being adapted for use in NZ. It is anticipated to be distributed in March 2021
- A consumer survey for DHBs is has been developed to assist DHBs to get consumer feedback
- Links continue to be developed with an international research group (RAPID) to look at interventions in PPC
- Urgent parent/ care information provided to PSNZ and KidsHealth webs sites re Covid-19
- Relationships with the NZ Epidemiology Service are being built on to attempt to identify the future needs for paediatric palliative care nationally
- To address equity issues, the CRG is organising a road show to improve knowledge and understanding of paediatric palliative care nationally
- Additional clinical positions have been identified in the South Island and the CRG is working to engage these people in the Clinical Network and ensure collaboration going forward.
- The continued presence and changing of the COVID 19 pandemic remain a concern with such a vulnerable service and patient group

Newborn (2012) www.starship.org.nz/newbornnetwork

Clinical Lead and CRG established. Work plan and achievements include:

- The CN is involved in service specifications for NZ Units
- The electronic system that provides updates on levels 2, 2+ & 3 units on cots utilisation has been reviewed and the system updated
- Facilitated the development of a multidiscipline professional peri-viability group to develop a NZ consensus statement that includes a resource for families. The resource has been loaded on the CN's webpage and profiled in January 2020 edition of CYNET <https://www.paediatrics.org.nz/resources/cynet-newsletters-presidents-message/show/1079>

- Established links to Maternal-Fetal Medicine group
- MoU developed with NZCOM
- Developed a shared interest with Neonatal Formulary group with a view to share resources and expertise as opportunities arise (remains a work in progress)
- Developing/producing three practice recommendations, consensus statements or guidelines per year.
 - Under biennial review: Dextrose gel; Screening for Retinopathy of Prematurity; Oxygen saturation; Transportation guidelines
 - Completed and loaded on the website in 2019 & 2020: Neonatal Encephalopathy; Subgaleal Haemorrhage Practice Recommendation; Periviability Consensus Statement; LISA-MIST Practice Recommendation & Video; Dehydration in the newborn practice recommendation; Red reflex assessment consensus statement (investigating the development of a supporting video)
 - Completed, but not yet loaded on the website: Audit of Congenital Diaphragmatic Hernia
 - Under development: Routine follow-up of preterm infants; 'Consent'
- Three resources on KidsHealth (Home Oxygen for Infants, Home Oxygen what else should I know and Apnoea of Prematurity) are being updated MoH supported external contracted review of Neonatal Intensive Care Units complete with report received early 2019. The CN has been involved with key stakeholders (e.g. DHBs and MoH) to agree an implementation plan to roll out a Transitional Care programme
- Horizontal links with the Paediatric Palliative Care, Intersex, Cerebral Palsy and Child Development & Disability CNs
- Urgent parent/ care information provided to PSNZ and KidsHealth websites re Covid-19
- Discussions held with the National Screening Unit about Oxygen saturation screening and project funding has been confirmed to conduct a survey
- A proposal is being drafted to support information sharing (learnings) about incidents that occur in District Health Board (DHB) Units

Gastroenterology (2013) www.starship.org.nz/gastroenterologynetwork

Clinical Leader and CRG established. Work plan developed from initial plans of the MoH/National Health Board's Technical Advisory Group. Work plan and achievements include:

- Guidelines for the improvement of treatment & management of inflammatory bowel disease (IBD) have been reviewed with amendments being made prior to reloading on the website
- The CRG remains active on several Pharmac committees to advocate for paediatric IBD needs
- An MoU between the CN and the endoscopy working group giving paediatric specific advocacy
- The CN continues to provide support for the National Intestinal Failure Service and collaborate where possible and appropriate
- New opportunities have been identified to continue to raise awareness and early diagnosis of conjugated jaundice including midwife study days and the GP conference. Note: the very positive outcome when an LMC provided early intervention and thereby reducing significant health issues (& costs) to the baby, family and sector
- A Jaundiced Baby Referral Pathway has been developed with multiple organisations and is available on the website (currently under review)
- Work regarding reflex testing of high bilirubin in babies with prolonged jaundice continues
- The biliary atresia management guideline has been completed and is on the website
- A Parent Guide to Alagille Syndrome has been drafted and is undergoing final review
- Development/ updates to a range of nursing and parent education resources; shared on the website and with relevant organisations
- A Coeliac disease referral pathway has been developed for the northern region which reduces the need for endoscopy for diagnosis. In partnership with MoH, planning is progressing to support national implementation
- Paediatric Endoscopy Standards of Care document awaiting ratification by NZ Society of Gastroenterologists
- Significant gains have been made in lab processes in some geographical areas (7 DHBs) for automating additional testing which assists in identifying Biliary Atresia (or other similar disease processes) and in flagging abnormal results more clearly to clinicians. This work has been published in a clinical laboratory journal and the cost benefit has been assessed as effective. A briefing paper is being developed for the MoH Child Health Advisor about the changes in surgical approach to Biliary Atresia, which have led to a significant change in the success of Kasai corrective surgery, which in turn should influence, delayed or reduced numbers of children requiring transplant(s).
- Currently there is significant variation in psychosocial services available for children with chronic conditions throughout NZ. The CRG are developing a paper to advocate for equitable service provision nationally
- There is now paediatric and CRG representation on the NZ Society for Gastroenterology working group for Endoscopy standards. Significant challenges remain to achieving national standards

- The CRG has commenced discussion with the Allergy CN and with Australian clinicians to collaborate in resource development for the management of Eosinophilic Oesophagitis
- A case study from the CN was published in the March 2017 CYNet
<https://www.paediatrics.org.nz/resources/cynet-newsletters-presidents-message/show/904>

Cystic Fibrosis (2014) www.starship.org.nz/cysticfibrosisnetwork/

Clinical Lead, Facilitator and CRG established. Work plan and achievements include:

- The CRG includes two representatives from Cystic Fibrosis NZ. This supports the integrated approach to cross-sector CN activities and provides a consumer voice.
- The sharing of a range of resources and information (registered numbers only) from the CF data base. Includes CFNZ's Referral Form now loaded on the website
- Significant work continues to review, update and load guidelines on the website. The CRG members are currently identifying strategies to further embed the guidelines throughout the healthcare system and this will be the focus in 2021
- Plans in progress to develop video tutorials on technical topics
- Review and update of information and resources on KidsHealth
- In discussion with NZ Formulary and NZ Formulary for Children regarding having a Cystic Fibrosis 'chapter' as part of their online service. This would be very useful as it would assist with updates, PHARMAC criteria and it is now the main source for pharmacy prescribing
- The CRG is actively engaging with the consumer representatives and PHARMAC to facilitate new medications for the treatment of CF in NZ
- Collaboration between the CRG and CFNZ has resulted in a significant number of Covid-19 information updates and resources developed and disseminated via the CFNZ website
- The CN continues to identify opportunities to lobby where appropriate to improve the quality of care for children with CF nationally

Sleep Medicine (early 2015) <https://www.starship.org.nz/sleepnetwork/>

Clinical Lead, Facilitator and CRG established. Work plan and achievements include:

- Comprehensive and abbreviated guidelines have been finalised and loaded on the website. These are now due for review and the CRG are considering how to progress this large piece of work
- Oximetry workshops (for DHBs) continue to be offered and undertaken upon request
- A resurvey of the 2013 National Sleep Medicine Facilities survey was done in 2017. The results were published as a poster at the Annual Scientific Meeting of the Paediatric Society of NZ, Nelson 2018. Letter written to MoH outlining findings and concerns; copied also to all CEOs of DHBs (and to lead paediatricians and ENT in each centre around the country)
- A meeting held with the Minister of Health to profile the very limited resources in NZ for paediatric sleep medicine
- Ongoing review of the KidsHealth website resources plus those on the MoH site. Also developed an information leaflet on Melatonin which has been loaded on the KidsHealth website
- A list of Sleep Medicine related conferences is maintained and loaded on the website
- Involvement in the national working group on weight related comorbidities assessment and management pathway
- Continue planning to revisit appropriate targets for surgical ENT treatment for OSA as highlighted with MoH in Sept 2019
- An online learning tool for oximetry for paediatricians, paediatric and ENT trainees and physiologists, based on the Australasian Sleep Association (ASA) technical specifications and interpretation document with case-based learning has been completed. has been completed and loaded on the website. Feedback from participants who have used the tool has been positive. The tool will be revised as necessary.
- Research proposal under development to focus on understanding barriers to recognition and treatment of paediatric OSA for Māori and Pacifica children, aiming to have outcomes that will guide how we can best address current inequities
- The CN is reviewing Health Promotion Agency resources
- Survey completed of all DHBs for feedback on a potential solution of a 3-centre hub and spoke model of care. Plan to revisit this with MoH
- Links to pertinent websites added to the CN's webpage
- Surveyed Paediatric and ORL specialists in all DHBs to gather data and generate a clearer picture of how DHBs currently handle referrals for children with sleep issues and disorders and access paediatric sleep medicine services. Analysis and presentation is a work in progress
- Continue to review 2018-19 data (via HQSC and NZ Child & Youth Epidemiology Service) for Tonsillectomy by DHB for Obstructive Sleep Apnoea

- In the development stage of research, a proposal to focus on understanding barriers to recognition and treatment of paediatric OSA for Māori and Pacifica tamariki /children, aiming to have outcomes that will guide how we can best address current inequities
- Continue the drive to improve the quality of increasing number of sleep studies undertaken on children in adult sleep laboratories and in private practice

Neurology (late 2015) <https://www.starship.org.nz/neuronetwork/>

Clinical Lead, Facilitator and CRG established. Work plan and achievements include:

- Good uptake/interest in Paediatric Epilepsy Training (PET) course by Paediatricians nationally and some international interest. Continuing to develop a sustainability strategy to support the course delivery within existing (unfunded) resources. Covid-19 has stopped further plans to increase numbers of PET educators which requires educators from UK to train the trainers
- New Zealand invited to join a multi-centre working group to develop a streamlined AusNZ Paediatric Stroke protocol. Due to Covid-19 there have been delays in moving this activity along
- Further guidelines on Ketogenic Diet are in process of being developed.
- Published Epilepsy guidelines, Idiopathic Intracranial Hypertension, Microcephaly and care for Duchenne Muscular Dystrophy guidelines in review by main authors. Epilepsy guidelines and Microcephaly in final review before re-publication. A working group to be established to develop a new action plan for Epilepsy.
- Work ongoing to align Epilepsy guidelines with Health Pathways, there will be three pathways: Febrile seizures, New onset seizures and Established epilepsy. These are currently awaiting review. Covid-19 has delayed progress on this.
- Patient/family information resources have been developed for Epilepsy and Neuromuscular and have been aligned with KidsHealth website
- A very successful Neuromuscular Forum for Allied Health Professionals was re-established in May 2019 to enhance and update previous training. Aim to continue forum on a yearly basis with the next forum planned for May 2021
- Continue to identify a Cognitive Behaviour Intervention for Tics Therapy (CBIT) guideline for children with Tourettes/TIC syndrome
- Review of ACC guidelines for anti-epilepsy drug (AED) usage in female patients completed
- Plan to develop a working group to progress discussions and action plan around transition from paediatric to adult services within the Neurology sector

Tube Feeding (2015 – Dec 2019) <https://www.starship.org.nz/tubefeedingnetwork/>

- This CN transitioned to a PSNZ Special Interest Group and ceased as a CN on 31 December 2019
- Resources remain available on the website

Allergy (Nov 2015) <https://www.starship.org.nz/allergynetwork>

Clinical Lead, Facilitator and CRG established. Work plan and achievements include:

- Surveys seeking feedback from urban, rural, general practice and public health nurses and dietetics is complete and results analysed. The report and recommendations have been approved and these will be developed into actions in the work plan
- Numerous resources developed and/or reviewed (CRG & Australasian Society of Clinical Immunology and Allergy (ASCI)) and loaded on the webpage
- Approval received to place a link to the Irish Food Allergy Network on the Allergy CN webpage
- Information /resources on KidsHealth site have been developed including ongoing Care and Transition to GP care
- This CN operates closely with the Eczema CN
- Allergy CRG members involved in GP Allergy Update held in Wellington in November 2018
- The Network works closely with the NGO 'Allergy NZ' including liaising re their communication with NZ School Nurses Assoc re EpiPens in schools
- A survey of dietitians (re primary care access to dietitians) has been completed and the final report will be available in the near future
- Anaphylaxis information on Health Navigator reviewed
- The CRG includes representation from Plunket Society
- Communication plan updated with new contacts and includes new resources primarily for primary/community care health professionals
- Goodfellow Unit online module on Cow's Milk Allergy for health professionals completed and will be linked/promoted on Allergy CN website

Intersex (Aug 2017-June 2020)

- This two-year project ceased on 30 June 2020 and a final report was provided to the MoH July 2020.

- Guidelines for a newborn baby with 'Differences in sexual development' based on principles of best practice, have been published on the Starship Neonatal Guidelines website (20/10/2020) <https://www.starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema>

Cerebral Palsy (June 2019)

Initial development has commenced on this specialty with the intention for the CN to become a work stream under an overarching Child Development and Disability CN. This remains a work in progress

- Clinical Lead/chair has been confirmed, the CRG established and a Facilitator appointed
- Terms of Reference and work plan have been ratified
- The first meeting (face-to-face) was held in November 2019
- Five very active workstreams have been identified: Child & Youth Voices; Best Practice; Transition; CP Register; Selective Dorsal Rhizotomy (SDR) & Intensives. Activities include (but not limited to) developing therapy checklist and early diagnostic pathway (9 resources); collating recommendations from international guidelines and selected published literature to produce summaries of actions points for best practice related to transition from youth to adult services; and flowchart of possible routes to obtain information and referral for SDR overseas; and checklists (health professionals, service providers, adult healthcare)
- The CN has strong links with the Cerebral Palsy Society. CRG representatives have met with their new Board and an MOU is under development
- Well established links also with the Child Development & Disability and Newborn CNs.

Child Development and Disability (July 2019)

Co-chair/ Leaders confirmed, CRG established and a Facilitator appointed.

- In March 2020, a satellite day was held alongside the General Paediatric Update meeting. A similar satellite day is being planned as an annual event and will raise the profile of the CN, its work and the needs of children and young people with disability
- Terms of Reference have been ratified
- The final work plan is in an advanced stage of development
- A number of work streams have been identified (including Attention Deficit Hyperactivity Disorder; Consultation to MoH; Down Syndrome; Member engagement; and Follow-up of for high risk babies (with the Newborn CN) and are progressing well
- A business case for a literature review related to therapy intervention in Down syndrome to inform practice guidance development has been successful and will enable this workstream to develop a robust resource
- Communication continues with other networks to share information and strengthen outcomes.
- The database of those interested in child development and disability has grown substantially over the last quarter as the "Lunch and Learn" sessions are well attended and raise awareness of the network

Paediatric Rehabilitation (2013 – remains 'on hold)

- Face-to-face meeting with key clinicians held 2014
- Due to the complexities involved a network will involve a range of subspecialties and various organisations who have an interest in rehabilitation services for children, e.g. ACC, disability services, multidisciplinary teams, education services and others
- Meetings held between the Spinal Cord Injury Prevention group & the NZCYCN Governance Group
- The option of having a single focus approach to some aspects of rehab services explored, e.g. guidelines for use of Botox. On hold meantime
- Internal processes with DHBs will inform and or support this network in the future.

Communication

A range of communication links have been developed. These include but are not limited to:

- CYNNet, the NZCYCN's newsletter, a publication is produced 6-monthly with the aim to provide updates on the NZCYCN Governance Group, the development and updates of the CN(s), case studies and or positive care outcomes resulting from resources / information development the CNs. CYNNet is distributed via PSNZ web site, all CN email lists; DHB Child Health Managers and Clinical Leaders, MoH links, interested and aligned professional groups, agencies and organisations (as known) <https://www.paediatrics.org.nz/news/cynet-newsletters-and-presidents-messages/>
- Development of a website that provides updates on behalf of all the CNs re; guidelines; practice recommendations; information of a range of care processes; education links. Ongoing support for the web site's NZCYCN pages is provided by the Auckland District Health Board's management team at Starship Children's Health <<https://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/>
- A revised website for the PSNZ <http://www.paediatrics.org.nz/> has been completed and site is designed to enable enhanced communication/information sharing through the 'Discourse' platform

- Newsletters and updates developed and shared by individual CNs to their extended networks and colleagues
- Presentations to relevant workshops and conferences are noted via the CN and/or the PSNZ site
- As able meetings are held with the (national) Child Health Managers' Group. A list of 'named' managers is regularly reviewed. Communication with this group helps facilitate the sharing of information on network development(s) and or updates
- A very positive article about the Clinical Networks was written by Prof Steve Cropper (Keele University and Partners in Pediatrics, UK) and published in the March edition of CYNET <http://www.paediatrics.org.nz/files/2017%20Documents/CYNet%20Newsletter%20-%20Issue%201%20April%202017.pdf>
- The NZCYCN Annual Reports 2017 – 2018, 2018 – 19 and 2019 -2020 are available on the MoH, NZCYCN and PSNZ websites [NZ Child and Youth Clinical Network - The Paediatric Society of New Zealand](#)

Challenges	Enablers
<ul style="list-style-type: none"> • That the NZCYCN is useful and acceptance by all clinicians • Acceptance by senior DHBs team and managers • Introduction(s) and acceptance by primary care and NGO sector • National funding model • Geographic spread of population base • Political pressure for single/small services • Time to establish a 'formal' network structure and move to consolidation and 'business as usual' stages – this takes time and will flounder if not supported • As the programme is a quality improvement operations what is the life of a Network? • How to exit established Network's operations and the challenge of how they will continue without limited secretariat support • Political environment – both a plus and minus • The 2020 international pandemic, Covid-19, and the impact on how local, national and international health care will be provided in the foreseeable future 	<ul style="list-style-type: none"> • Considerable and ongoing discussion with PSNZ membership and multi-agency stakeholders • The 2016 – 2020 PSNZ Strategic Plan will provide visible support to the value of NZCY Clinical Networks • Senior MoH policy support to improve integration and collaboration within and between sectors • MoH Strategic Plan/Direction and emphasis on increasing national and local integration and collaboration • The need to function closely with local providers and DHB staff, to build capacity and capability as close to home as possible, e.g. through workforce development, resources, electronic links • Profile achievements, positive stories on successful outcomes, family and staff satisfaction levels • Mentor CN leads/ chairs and provide overarching facilitation and support • Building support and maximising shared learnings with international child and youth network programme • Since the advent of the Covid-19 pandemic, opportunities have developed to facilitate and redefine how previous 'face-to-face' meetings are held, facilitating remote type 'clinical assessments', promoting cloud based education forums and other meetings. This has resulted in greater acceptance of Zoom / webinars / Microsoft meeting rooms and other mediums to support activities that, until the impact of the Covid-19 challenge, have not always been readily accepted. This changed way of using cloud-based links to provide health care, education and the sharing of expertise remains a 'work in progress', but has, and will continue to provide, new ways of working. A plus from these changes is the saving that can be reinvested in front line care.

Overview of support through the Secretariat and related activities

- Continued administrative and facilitation support to all CN functions
- Development of a comprehensive range of resources to help clinical network development(s) and operational structures(s)
- Development of and regular reviews of a 'Profile of Clinical Networks for Children and Youth in NZ' – on the PSNZ web site
- Links with all PSNZ Special Interest Groups
- Practical support for NZ Child and Youth Epidemiology Service
- As able and practical the alignment of CNs with various MoH strategic documents, e.g. Better Public Services targets; the 2016 MoH Health Strategic Plan and the associated Road Map of Actions; the quality

improvement framework 'The Triple Aim'; and within each NZCYCN the development and tracking of Key Performance Indicators and individual Strategic Plans

- Based on findings in the (externally reviewed) Evaluation Report of the NZCYCN Programme (2017), recommendations will be maximised as able
- Provide support to the Family and Community Health, Child and Community Health, Population Health and Prevention team at the MoH and being aware of the need to be a key stakeholder as Oranga Tamariki moves through various phases of change, including the developed of the various schedules to the MoU between, Police, Health and Social Development.
- Horizontal links with various organisations including but not limited to Midland Child Health Action Group; South Island Child Health Alliance; Northern Child Health Alliance, Central Technical Advisory Group and the Office of the Commission for Children to share initiatives and, as best able, reduce duplication of quality improvement activities

Sustainability, succession planning and the future

- Continued positive engagement with key MoH stakeholders
- Continue to encourage and support strong clinical leadership, provide management processes for network development, endeavor to promote widespread clinical engagement through formalised arrangements for care (e.g. work plan activities) and the reporting and sharing of results on the web site and other avenues
- Seek ways to increase support through KPIs. Note this can be difficult due to limitation of specialist metrics through DHB outpatient services
- Continue to seek support through NZCY Epidemiology Service
- Continue to promote support for the programme through DHB senior leadership teams, clinical directors and managers of child health services
- Provide achievement updates to senior MoH Directors and, as able, the Minister of Health
- Succession planning; as able and budget permits, devolve day to day responsibility to each CN
- Continue to provide (national) NZCYCN Secretariat support to champion and facilitate activities
- Development of links with Health Quality and Safety Commission to seek support on the how best to profile and evaluation the positive outcomes of early intervention and the benefits of capacity building in the sector.

Conclusion

During the 11-year tenure of the contracted NZCYCN programme, a comprehensive range of structures have been developed to support '*The Strategic Development of Child and Youth Clinical Networks*'.

The NZCYCN is a quality improvement programme, is clinically led from a 'needs based' position, is aligned with the MoH's direction for child and youth health care and is making difference in how multidisciplinary professionals may seek expert advice to address some of the challenges experienced when providing specialised front-line care across urban and rural environments. The NZCYCN programmes enables a more equitable base from which clinicians across New Zealand can seek expertise to provide front line care 'closer to home'

It is important to note that the development, and consolation, of a clinical network takes time (e.g. years not months) and if left unsupported will likely flounder. For further information please contact Mollie Wilson mollie@healthnetworks.co.nz

Appendix 1: New Zealand (national) Child and Youth Clinical Network Programme's Governance Group¹⁰

Membership list at March 2021:

Dawn Elder	Chair, Governance Group, Professor and HOD, Department of Paediatrics and Child Health, Otago University, Wellington School of Medicine (2/2014 – 1/2019). Changes in role responsibilities (Chair from August 2020)
Nicola Austin	President PSNZ Neonatal Paediatrician, Canterbury DHB
David Barker	Paediatrician, Northland DHB (12/2018)
Barb Bradnock	DHB GM Planning and Funding representative (1/2019)
Megan Bryant	Consumer representative, member of the Christchurch DHB Child Health Advisory Council (8/2020)
Bridgette Farrant	Adolescent Physician, Society of Youth Health Professional Aotearoa NZ (SYHPANZ) Representative (June 2020)
Fiona Graham	Occupational Therapist; Senior Lecturer, Rehabilitation Teaching & Research Unit, University of Otago (11/2017)
Cameron Grant	Paediatrician, Starship Children's Health, Professor in Paediatrics, The University of Auckland (6/2019)
Toriana (Tori) Hunt	Kaiāwhina Whaea me Ngā Pēpi (Māori Health Advisor for Women and Babies), Christchurch Women's Hospital (8/2020)
Tim Jelleyman	Child Health Advisor, Ministry of Health (2/2020)
Mal Joyce	Chair, Child Health Managers Group; Manager, Child Health Service, CCDHB (8/2013)
Jane O'Malley	Chief Nurse, Royal New Zealand Plunket Society (4/2018)
Mary Roberts	Operations Lead, Moana Research (3/2016)
Pat Tuohy	Independent Paediatrician (April 2020)

In attendance

Mollie Wilson	CEO, Paediatric Society of New Zealand
Denise Tringham	Secretariat, Paediatric Society of New Zealand
Leonie McCormack	Manager, Family and Community Health, Child and Community Health Population Health and Prevention, Ministry of Health (9/2019)
Grant Pollard	Group Manager, Child & Community Health, Population Health & Prevention, MoH (2020)
Karyn Sanson	Operational Project Manager, NZCYCN Programme (5/2016)

Resignations:

Clinical representatives for youth services; Dr Simon Denny, Dr Teri-Ann Clark, RN Shaz Iseli, held Governance Group appointments based on their involvement in primary care and teaching roles for youth services. Regrettably, due to workload requirements their resignations were received during 2012/2014 period

Maureen Ager	RN, RM, and Bi Cultural advisor to HBDHB. Seconded 8/2013 for a 6-month period. Richard Aickin Emergency Medicine Specialist, Starship Children's Hospital, ADHB (2010, Chair from July 2014-August 2020)
Nick Baker	Clinical Director, Child Health, Nelson/Marlborough DHB. Resigned August 2013 due to change in role at NMDHB
Jon Buchan	Portfolio Manager, Whanganui DHB (9/2014 – 12/2018). Change in role
Danah Cadman	Interim General Manager, Starship, ADHB. Seconded for 6-month period from 2013, resigned 6/2014 due to change in role
Julie Chambers	Senior Advisor, Child Injury Prevention, ADHB (2010-08/2018)
Kate Chong	MoH National Programme Manager, Child & Family Programmes,(3/16–3/17)
Glenn Doherty	GP & Medical Director, Tongan Health Society Inc., Auckland (10/14 - 2016)
John Forman	Executive Director, NZORD, Appointed 2010, Resigned December 2014
Trish Hastie	Consumer Representative. Member of the CDHB Child Health Consumer Group (8/2017 – 12/2019)
Toriana Hunt	Kaiwhakamahere Hauoro Tamariki, Child Health Advisor for Maori, Canterbury DHB (8/2018 – 12/2019)
Tim Jelleyman	President PSNZ and Paediatrician Waitemata, DHB (11/2017 – 11/2019)
Rosemary Marks	Paediatrician, ADHB (Past PSNZ President & inaugural Governance Group chair for 6 yrs, member of the Governance Group; 2010 – 12/2018)
Josette McAllister	Senior Advisor, Child and Family Programmes, Integrated Service Design Service Commissioning, Ministry of Health (9/2018 – 3/2020 due to taking 12 months leave)
Chris Moyes	Paediatrician, Bay of Plenty DHB 2010 – 6 /2018

¹⁰ Inaugural members (2010) are those who have no date alongside their name

David Newman	Paediatrician and past PSNZ President (2015 – 2017)
Kate Russell	Consumer Representative, Chief Executive Canterbury Medical Research Foundation NZ Brain Research Institute. (11/2014 - 2017)
Vili Sotutu	Paediatrician, Southern DHB; 2014 - 12/2015. Resignation due to role change
Barry Taylor	Deputy Chair, Professor of Paediatrics & Child Health, Otago University. Resigned 11/2013
Gary Tonkin	MoH, Senior Portfolio Manager 2014 – 8/2015
Pat Tuohy	Chief Advisor, Child and Youth Services, MoH. Retired from MoH 31/7/2019 (2010- 7/2019)
Laura Warwick	Advisor, Child and Family Programmes, Integrated Service Design, Service Commissioning, MoH. (March 2017 – 8/2018)