

ANNUAL REPORT

1 JULY 2019 – 30 JUNE 2020

NEW ZEALAND CHILD AND YOUTH CLINICAL NETWORK



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.
KPI	A key performance indicator is a type of performance measurement that acts as a compass, helping you understand how you are performing towards strategic goals.
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

Disclaimer

This publication informs discussion and assists New Zealand's child health service development. The opinions expressed in the publication do not necessarily reflect the views of the Ministry of Health. All care has been taken in the production of this publication. Information and related data were accurate at the time of release but may be subject to change over time as more information is received. It is advisable to check the current status of figures with the Paediatric Society of New Zealand (PSNZ) before quoting or using them in further analysis. The PSNZ makes no warranty, expressed or implied, nor assumes any legal liability or responsibility for the accuracy, correctness, completeness or use of the information or data in this publication. Further, the PSNZ shall not be liable for any loss or damage arising directly or indirectly from the information or data presented in this publication. The PSNZ and the New Zealand Child and Youth Clinical Network Programme welcomes comments and suggestions about this publication.

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Chair's Message



After six years as the Chair of the Governance Group, and being a member of the Group since the 2010 inaugural Advisory Group (recent name change to Governance Group), Dr Richard Aickin stepped down from this role at the end of July 2020. The following brief snapshot of change and Network updates in the past 12 months therefore reflects his excellent leadership in the role and not mine, but I am very much looking forward to having an overview of the work of the Programme as it continues over the coming years in my role as Chair.

The NZCYCN program continues to develop and the Governance Group is extremely grateful for the willingness of all the individual network members who commit considerable time, energy and expertise to make this happen. All the Networks have been busy through this period and several of their achievements are profiled in the following pages. Currently there are 12 Networks and two Networks have completed specific terms during this period. Plus two new Networks have been established, the Cerebral Palsy and Child Development and Disability Clinical Networks.

Like most other health services, Covid-19 has impacted on how all the Networks have functioned in recent months. However, although all face-to-face meetings have been postponed, the number of Zoom communications has significantly increased and, to varying extent, Network activities have continued to be progressed. Sincere thanks to all for addressing the many challenges the pandemic has created in already busy clinical workloads.

During the past 12 months, Dr Pat Tuohy has returned to the Governance Group in an independent role. In his previous Ministry of Health (MoH) role, Pat was a member of the Governance Group and, with his return, his expertise and knowledge of cross sector issues associated with child and youth health is acknowledged and very much appreciated. Welcome also to Dr Tim Jelleyman in his new role as Child Health Advisor to the MoH and to Dr Bridgette Farrant, Adolescent Physician and Society of Youth Health Professional Aotearoa NZ (SYHPANZ) Representative. Their expertise will also add considerable value to the Group. During the year Toriana Hunt, bicultural advisor, and Trish Hastie, consumer representative, stepped down from the Governance Group. Both have provided expert advice on a range of matters during their tenure on the Governance Group.

Network quality improvement resources and related information continue to be loaded on the Starship website and within this report more detailed information can be viewed on the value of this core Network activity. Several Networks are also involved in improving resources for whānau through the KidsHealth website. These communications are a vital part of the work of the Networks.

This work does not happen without a strong team at the core and I would like to thank Mrs Mollie Wilson for all her work keeping the programme on track as well as the secretariat and project management support that assists her. Despite our significant progress, there is still much to be done to ensure that the services available for children and youth in Aotearoa with health needs are equitable, accessible and evidence-based. Children are our taonga and if we can ensure their health needs are fully met, then we know that we are providing the best start to the rest of their lives.

Ki te kore nga putake e mākukungia e kore te rakau e tupu

If the roots of the tree are not watered the tree will never grow

Ngā mihi

Professor Dawn Elder

Chair, NZCYCN Governance Group.

The Ninth Annual Report for the Programme

While this is the ninth annual report to MoH, this is the third report in this format.

INTRODUCTION

In 2008 the Paediatric Society of New Zealand (PSNZ) discussed with the MoH the value of developing national child and youth clinical networks. A contract was subsequently developed between MoH and the PSNZ and a range of deliverables were agreed. These included incorporating the benefits of networks, sector consultation and the development of a formal process for a New Zealand, national network development programme.

WHY DEVELOP NATIONAL CLINICAL NETWORKS?

A range of international papers describe¹ the benefits and changes of clinical network (CN). These include:

- To strengthen clinical leadership nationally and locally
- To provide 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 and between horizontal and vertical continuums of care / networks
- To seek new forms of association /integration between institutions, often based on care pathways or joint assessments
- A belief that a networked approach can help share risks, reduce costs to member institutions and/or improve health outcomes
- To facilitate family-centred care models based on cooperation and provide more specialist care or care support by specialists through generalist child health practices, closer to home
- To provide an effective and efficient platform on which to build and support workforce capacity that include early intervention and primary care elements
- To support development of multi-disciplinary teams at all levels
- To endeavour to utilise technology in terms of communication and to monitor outcomes
- To facilitate attempts to remove perverse incentives and promote best health outcomes.

From this quality improvement initiative, the programme was created.

1 Reference NHS (1999) – Scottish Executive Guidance. 12 Core Principles of MCN. 2 <http://adc.bmj.com/content/98/11/84>. 3 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. 4 The full report can be viewed at <http://www.paediatrics.org.nz/>

ABOUT THE NZCYCN PROGRAMME

The PSNZ has a contract with the MoH to development and implement 'A strategic approach to national clinical networks for child and youth health services.' This is a quality improvement programme and a comprehensive range of formal processes support the initiation, development and consolidation of each CN.

STRATEGIC DOCUMENTS

Several documents inform and support the programme's development and continued operations. These include, but are not limited to:

- 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'²³
- The Evaluation Report⁴ on the *Development and Implementation of the New Zealand Child and Youth Clinical Network Programme (2017)*
- NZ Government and Ministry of Health requirements due to the Covid-19 pandemic.

GOVERNANCE AND ACCOUNTABILITY

The contract required the appointment of a Governance Group to provide strategic authority and support the contract's operations. The MoH approves the appointment of the Governance Group Chair and membership of the Governance Group is representative of a range of multidisciplinary professional leaders from the sector. Geographical and urban/rural membership is reflected in appointments. (See Terms

of Reference (ToR) and Governance Group membership in Appendix 1).

Usually up to three face-to-face meetings are held annually, interspersed by six-weekly Zoom conference calls; however, the Covid-19 pandemic has required meetings to be held via Zoom links for all NZCYCN operations since mid-March 2020. One of the face-to-face meetings in 2019 was a shared workshop between the Governance Group, the CN leaders and 'Facilitators.'



SECRETARIAT, SUPPORT AND REVIEWS

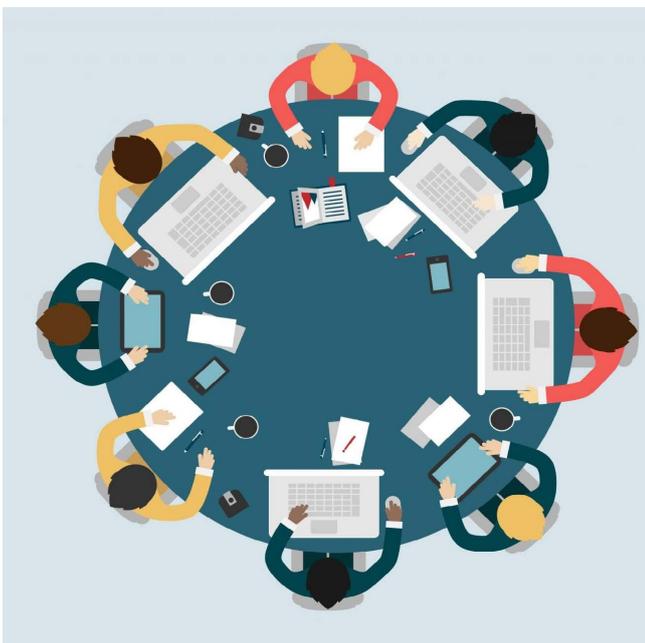
A small secretariat provides administrative support for the programme and a Facilitator role has been developed to support each Network. The Facilitator role is undertaken by an expert specialist who provides additional support to each CN to progress the agreed deliverables, key performance indicators and provide quarterly reports on activities and/or achievements. Included in the reporting is feedback on the high-level deliverables detailed in each CN's Strategic Plans.

The programme established links with a 'like type' UK programme and a comparative, informal academic overview of the New Zealand programme was positive⁵.

Additionally, an independent, formal evaluation report on the NZCYCN Programme's contracted deliverables has been completed and records that the contractual requirements are being met.

SECTOR CONSULTATION AND COMMUNICATION

To ensure the voice of New Zealand's child and youth health's multidisciplinary (MDT) clinicians was heard, four regional meetings attended by 175 child and youth health professionals were held early in the programme's development. The themes developed at these meetings informed the programme's core aim which was to develop a successful national child and youth health quality improvement programme. The themes proposed at the regional meetings included; the development of guidelines / protocols / best practice recommendations; shared workforce development opportunities; integration of care across District Health Boards (DHBs), other health organisations and professional bodies; improved metrics to demonstrate to the required health services the value of the provision of current and future care. Activities that reflect these themes are demonstrated in each CN's Work and Strategic Plans.



WHAT ARE THE NZCYCN PROGRAMME'S ACHIEVEMENTS FOR THE PERIOD JULY 2019 TO JUNE 2020?

On the following page is a summary of developments in the past year.

The Strategic Plans of all the Networks are aligned to the structure outlined in the Ministry of Health's 2016 Strategic Direction and Road for Action and these are regularly reviewed. The following table is aligned to each Network's Key Performance Indicators that in turn are aligned to each CN's Strategic Plan. A summary of achievements and 'work in progress' is profiled.

⁵ Cropper, S article in NZCYCN Programme's March 2017 CYNet publication.

TABLE 1. A SUMMARY OF THE NZCYCN PROGRAMME'S CLINICAL NETWORKS' ACHIEVEMENTS ALIGNED KEY PERFORMANCE INDICATORS (KPIs)

This table outlines some achievements of the CNs within the NZCYCN programme for the period ending 30 June 2020.

Since the programme's inception, a number of achievements and operational processes have been completed or remain a 'work-in-progress'. These include, but are not limited to:

	<p>12 subspecialty Clinical Networks (CN) were operational at the end of the period: Child Protection, Palliative Care, Diabetes, Eczema, Newborn, Gastroenterology, Cystic Fibrosis, Neurology, Sleep Medicine, Allergy, Cerebral Palsy and Child Development & Disability.</p> <p>Two subspecialty CNs disestablished by the end of the period: Tube Feeding, Intersex.</p>
	<p>The first Clinical Network was established late 2010 and by June 2020, 12 CNs were in varying phases of consolidation and two have been disestablished.</p>
	<p>CNs usually engage in one or two face-to-face meeting annually; however, these were discontinued from March 2020 due to Covid-19.</p> <p>Covid-19 has also affected the availability of some clinicians to engage in Zoom video conference meetings while others were able to participate in more frequent meetings.</p>
	<p>Over 250 website resources/best practice recommendations/links to related websites have been established and videos can be viewed at www.starship.org.nz/for-healthprofessionals/new-zealand-child-and-youth-clinical-networks/ The total includes more than 62 contributions to the KidsHealth site. To retain currency, all resources have a review date.</p> <p>The online publication on the Starship website is supported by the DHB's senior management team.</p>
	<p>The biannual publication of the programme's newsletter CYNet has continued. CYNet profiles activities, new developments and acknowledged clinical leadership changes www.paediatrics.org.nz</p>
	<p>All CNs have a nominated clinical leader (or chair) and a MDT 'Clinical Reference Group' (CRG) that agrees the deliverables for that CN's work plan, key performance indicators (KPIs) and their Strategic Plan.</p> <p>All CNs provide quarterly reports on KPIs and work plan achievements.</p>
	<p>By June 2020, more than 200 MDT members and consumers had or were continuing to contribute to the various clinical networks and or supported a range of activities.</p>
	<p>Contracted 'Facilitator' support is provided to each CN to assist the leader(s)/chairs, and CRGs with activities.</p>
	<p>50% of the subspecialty CNs have been developed at the request of MoH.</p>
	<p>Established formal links with the 23 PSNZ Special Interest Groups (SIGs), KidsHealth Parent Information website, NZ Child and Youth Epidemiology Service, regional health alliance groups, RNZ Plunket Inc, Telemedicine Trust, DHB Child Health Managers & Portfolio management groups, the Violence Intervention Programme and a range of other professional organisations.</p> <p>Established links with international network organisations and/or subspecialty clinical networks. Five formal memorandums of understanding/agreements have been established some of which were recently reviewed.</p>

The NZCYCN Programme's support for the Ministry of Health's Strategic Direction and Road Map for action.

The NZCYCN is a quality improvement programme designed to promote and support positive change in health service delivery.

A business case proposal underpins the establishment of a CN; all CNs have ToRs that inform their agreed Workplans, Key Performance Indicators and Strategic Plans.

Each Strategic Plan incorporates the MoH's 2016 Health Strategy Direction and the related Roadmap of Action.

The five MoH themes are:

- 1 People-Powered
- 2 Closer to Home
- 3 Value and High Performance
- 4 One Team
- 5 Smart Systems



The NZCYCN Programme's 12 CNs are noted below. Further information can be viewed on the CN website located on the Starship Children's Hospital platform via dedicated web pages

www.starship.org.nz/for-health-professionals/
Child Protection
www.starship.org.nz/childprotectnetwork
Palliative Care
www.starship.org.nz/palliativecarenetwork
Diabetes
www.starship.org.nz/diabetesnetwork
Eczema
www.starship.org.nz/eczemanetwork
Newborn
www.starship.org.nz/newbornnetwork
Gastroenterology
www.starship.org.nz/gastroenterologynetwork
Cystic Fibrosis
www.starship.org.nz/cysticfibrosisnetwork
Neurology
www.starship.org.nz/neuronetwork/
Sleep Medicine
www.starship.org.nz/sleepnetwork/
Tube Feeding
www.starship.org.nz/tubefeedingnetwork/
Allergy
www.starship.org.nz/allergynetwork
Cerebral Palsy
www.starship.org.nz/health-professionals/cerebral-palsy-clinical-network
Child Development & Disability (under development)

The table on the following page provides examples of outcomes and work in progress of each CN showing links to the five themes.



CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>CHILD PROTECTION</p> <p>Established 2011</p> <p>www.starship.org.nz/childprotectnetwork</p>	<p>Promote and support the building of clinical capacity and capability in the sector and enhance DHB involvement through shared, MDT, engagement</p>	<ul style="list-style-type: none"> • The findings of the survey about child protection services available in all DHBs was presented at the Child Protection SIG Satellite day in November 2017. • The findings from a questionnaire sent to Paediatricians regarding the challenges of practising Child Protection was published in 2019. • 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 working with the Oranga Tamariki Liaison Social Worker; 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 is currently under development. The MOU and Schedules are reviewed regularly to ensure currency with changes to legislation.
	<p>Promote the Clinical Network as the expert Governance Group in Child Protection within the health sector</p>	<ul style="list-style-type: none"> • The CRG is involved in the development of a joint policy on ensuring the safety of the unborn/ newborn child, provision of healthcare to young people in Oranga Tamariki residences, and the Oranga Tamariki Practice Framework External Governance Group.
	<p>Define role of the network in the ongoing management of NCPAS nationally</p>	<ul style="list-style-type: none"> • Operational management of the National Child Protection Alert System was contracted to a provider in January 2020. A Memorandum of Understanding has been developed with PSNZ for the CN to provide clinical leadership for the programme. 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.

CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>PAEDIATRIC PALLIATIVE CARE SERVICES</p> <p>Established. 2012</p> <p>www.starship.org.nz/palliativecarenetwork</p>	<p>Develop and maintain the Network's infrastructure and embed activities to ensure sustainability and continuous quality improvement</p>	<ul style="list-style-type: none"> • The CRG has adapted to the changes created by Covid-19 and the group has remained connected through monthly meetings using Zoom. A model incorporating shorter, single project focussed meetings has been implemented to make most effective use of the new meeting platform. • Membership on the CRG is regularly reviewed.
	<p>To enable nationally coordinated paediatric palliative care services to achieve: consistency of care around New Zealand; improved linkages between families, primary, secondary, tertiary care and allied health; clear guidelines and resources to support diagnosis and management in primary and secondary care; in particular support children with life-limiting conditions, and their families and whānau</p>	<ul style="list-style-type: none"> • The CRG have focused on ensuring clinicians and families have the information they need to continue to provide high quality care during the Covid-19 Pandemic. • Additional resources have been made available on the KidsHealth website. • A consumer survey, developed in Australia, has been adapted for use in NZ and been distributed • The successful monthly education sessions have continued, interest has remained high and multiple centres have joined regularly. In May, the sessions were changed to trial the Zoom platform and the effectiveness of this change will be assessed late 2020. • The Paediatric Palliative Care (PPC) End of Life Clinical Guidelines are currently being reviewed, some minor delays experienced due to Covid-19. • Working towards raising the profile of PPC nationally and develop direct links/contacts within MoH. • A new Memorandum of Agreement (MoA) with the Victorian (Australia) Paediatric Palliative Care Service has been completed. The Victorian team were impressed with the robust and rigorous process in the guideline development and review. • The MoA with Hospice NZ has been reviewed and renewed for a further 3 years.
	<p>Assist health professionals (and their employing bodies) to meet their respective duties and obligations to ensure that health consumers receive the appropriate standard of care</p>	<ul style="list-style-type: none"> • New links continue to be developed with an international research group (RAPID) to review interventions in PPC. National ethics approval for the program enable additions to the series to occur over an 8-year period. • One series has been identified because of the Covid-19 experience and an additional long-term international research project is also underway.

CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>CHILDREN AND YOUNG PEOPLE WITH DIABETES</p> <p>Established 2012</p> <p>www.starship.org.nz/diabetesnetwork</p>	<p>Support and equip patients and consumers to be informed and involved in their own health</p>	<ul style="list-style-type: none"> • The Diabetes in Schools resources, i.e. 'Action and Management Plans' and 'Exams and Diabetes' were updated. Funding has been obtained to develop a specific NZ branded resource to reduce complexity in the annual review. The NZ resource is separate to the Australian document. • Advice resources regarding children with diabetes and Covid-19 were developed and shared on the KidsHealth and other related websites. • To ensure consistent advice is provided, the CN is in the process of creating an MOU with Diabetes New Zealand.
	<p>Development and implementation of quality improvement activities to enable clinicians across the sector to use evidence-based guidelines</p>	<ul style="list-style-type: none"> • The CN has published an updated version of the clinical guideline for the management of diabetic ketoacidosis. • The CN is currently reviewing the clinical protocol for the management of children with type 1 diabetes who require peri-operative management. • The CN is endorsing the recently published APEG guidelines for the management of type 2 diabetes in children and adolescents. • The New Zealand Society for the Study of Diabetes's (NZSSD) combined Diabetes Dietitians and Diabetes CN professional development day, planned for this 2020, is postponed until 2021.
	<p>The CN encourages innovation, research and emerging technologies to build capability and capacity in the paediatric diabetes sector</p>	<ul style="list-style-type: none"> • Multiple collaborative research studies are occurring across the network.

CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>TREATMENT OF CHILDHOOD ECZEMA</p> <p>Established 2012</p> <p>www.starship.org.nz/eczemanetwork</p>	<p>Provide web-based guidelines and resources to support healthcare professionals</p>	<ul style="list-style-type: none"> • The video developed for KidsHealth website on bathing and application of ointments/creams has consistently received positive feedback. An updated video is delayed due to Covid-19. • The CN's resources are reviewed and revised regularly including pictorial handouts and other resources for prescribers and their patients. • Links to information on Eczema Care and Allergy prevention were added to the NZCYCN's website and referenced to KidsHealth website. • A resource on Eczema Myths & Facts has been drafted and provided to KidsHealth website. • A review information on Eczema care and treatment has been updated for Health Navigator.
	<p>Advocate for implementation of the model of care and seek feedback from the wider membership on the value of the model in their practice(s)</p>	<ul style="list-style-type: none"> • A 'Model of Care' has been developed and is on the website. The document is regularly reviewed and revised as required. A series of case studies on the use of the 'Model of Care' around the country has been completed, and an article in review for submission for publication.
	<p>Develop and support ongoing workforce development events</p>	<ul style="list-style-type: none"> • Education and Training section with links to courses available to health professionals is set up on the website including the new Goodfellow Unit module on Atopic Eczema. • A review of feedback from the Nurses Study Day identified a need for education and resources for Well Child Tamariki Ora Service providers. To progress this need RNZ Plunket was approached to nominate representatives to the CRG. A Plunket representative is now on the CRG. • A wider Eczema network is maintained that receives regular communications. • It is noted that the priority for the Eczema CRG is guidelines, resources, and support for workforce development in primary and community care and to address inequities for those in disadvantaged communities. Work on this priority area has been delayed due to the measles epidemic in the Auckland region and then Covid-19.

CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>NEWBORN</p> <p>Established 2013</p> <p>www.starship.org.nz/newbornnetwork</p>	<p>Develop and maintain the Network's infrastructure and embed activities to ensure sustainability and continuous quality improvement</p>	<ul style="list-style-type: none"> • An MoU has been developed with New Zealand College Of Midwifery. • A shared interest has been developed with the Neonatal Formulary group with a view to have agreed national monographs for medicines administered to neonates. • Horizontal links established with the Paediatric Palliative Care and Intersex CNs. • The website metrics demonstrates access to, or review of, the resources on the CN's web page and shows a high number of reviews of the LISA-MIST video. • A number of Neonatologists and Nurse Managers have participated in the CN - EPIQ (Evidence-Based Practice of Improving Quality) workshops held throughout NZ. Additionally, some clinicians have become facilitators for the course.
	<p>Enable nationally coordinated newborn services to achieve: Consistency of care around New Zealand; Guidelines and resources to support diagnosis and management in primary and secondary care; in partnership with MoH review the Service Specification</p>	<ul style="list-style-type: none"> • The CN has been, and continues to be, involved in supporting the MoH review of Service Specifications for NZ Units. • The electronic system that provides updates on levels 2, 2+ & 3 units on cot utilisation has been reviewed and a dashboard system has been proposed. • In 2018, the MoH and joint District Health Boards' (DHBs) Chief Executives commissioned a review of neonatal units in New Zealand, led by the Newborn CN. This review resulted in a commissioned project to progress 'Neonatal Transitional Care' in DHBs and this project ultimately resulted in a report to the MoH. The recommendations will require complex solutions and this work resides with the MoH and remains a 'work in progress'. In time the publishable report will be released on this significant work.
	<p>Deliver 3 Practice recommendation, consensus statements or guidelines annually</p>	<ul style="list-style-type: none"> • The CN facilitated the development of a multidiscipline professional peri-viability group to agree a NZ consensus statement. The development also included a resource for families. The resource has been loaded on the CN's webpage and profiled in the January edition of CYNet: https://tinyurl.com/y43dkoua • Under biennial review: Dextrose gel; Screening for Retinopathy of Prematurity; Oxygen saturation; and Transportation guidelines • Completed and loaded on the website in 2019: Neonatal Encephalopathy; Subgaleal Haemorrhage Practice Recommendation; Periviability Consensus Statement; LISA-MIST Practice Recommendation & Video; Dehydration in the Newborn Practice Recommendation. • Completed: Audit of Congenital Diaphragmatic Hernia outcomes in New Zealand; Red reflex Assessment Consensus Statement. • Under development: Routine Follow-up of Preterm Infants; 'Consent'. • Three resources were developed and loaded on KidsHealth ('Home Oxygen for Infants', 'Home Oxygen- what else should I know' and 'Apnoea of Prematurity'. • Urgent parent/ care information provided to PSNZ and KidsHealth websites re Covid-19.
	<p>To assist health professionals (and their employing bodies) to meet their respective duties and obligations to ensure that health consumers receive the appropriate standard of care</p>	<ul style="list-style-type: none"> • Activities to support this overriding KPI are included in the above activities and remain ongoing.

CLINICAL NETWORK	KPIs/ HIGH-LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>PAEDIATRIC GASTROENTEROLOGY SERVICES</p> <p>Established 2013</p> <p>www.starship.org.nz/gastroenterology_network</p>	<p>To develop and maintain clear guidelines and resources to support diagnosis and management of children with intestinal and/ or liver conditions and their families and whānau</p>	<ul style="list-style-type: none"> • Biliary Atresia Guidelines review has been completed.
	<p>To enable nationally coordinated paediatric gastroenterology/ hepatology services (e.g. biliary atresia, coeliac disease) to achieve: Consistency of care around New Zealand; and Improved linkages between families, primary, secondary, tertiary care and allied health</p>	<ul style="list-style-type: none"> • The proposed Biliary Atresia awareness strategies have been postponed due to Covid-19 as it involved attendance and speaking opportunities at conferences which were cancelled. • Coeliac disease work is on hold initially due to Covid-19; however, and despite the extra pressure on Laboratories, a number of DHBs have progressed their work towards a biopsy free diagnosis of Coeliac disease thereby reducing regional variation in care.
	<p>Provide information to health professionals that informs best practice to enable delivery of appropriate standards of care</p>	<ul style="list-style-type: none"> • The collaborative work with the Allergy CRG to develop a resource document for the care of children with eosinophilic oesophagitis has been postponed to December 2020.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>CYSTIC FIBROSIS</p> <p>Established 2014</p> <p>www.starship.org.nz/cysticfibrosis.network/</p>	<p>Provide information to health professionals that informs best practice to enable delivery of appropriate standards of care</p>	<ul style="list-style-type: none"> • Due to the nature of the roles crossing both health and education, and the impact of COVID 19 on this CRG, the collaborative work between these sectors is temporarily on hold. The impact was especially notable through the Covid-19 restrictions. • Covid-19 has also created opportunities to promote the need for improvements in the quality of care provided for children with Cystic Fibrosis nationally. • Information shared between Cystic Fibrosis NZ (CFNZ) and PHARMAC has enabled the CN to consider and support the request in regard to new medications. The CN was able to provide PHARMAC with patient numbers to enable more accurate financial costings, then provide support for the development of guidelines on the new medication use. The two new medications are a modifier drug (Ivacaftor) and a more appropriate formulation of pancreatic enzyme replacement for infants and pre-schoolers (Creon-micro).
	<p>To enable nationally coordinated paediatric Cystic Fibrosis services to achieve: Consistency of care around NZ; to improved linkages between families, primary, secondary, tertiary care & allied health</p>	<ul style="list-style-type: none"> • Collaboration between the CRG and Cystic Fibrosis NZ has resulted in a significant number of Covid-19 information updates, and associated resources, that have been disseminated via the CFNZ website. As the pandemic evolves, similar type updates will remain a priority in 2020. • PORT CF (the national database for CF) continues to gather data and has added a standardised form to enable requests for anonymised registry data. PORT CF functions under an ethics framework that enables it to support research projects, from any researcher from bona fide health and research institutions.
	<p>To identify and improve the quality of information available to guide clinical practice and care of children and young people with Cystic Fibrosis</p>	<ul style="list-style-type: none"> • The development of clinical guidelines had been progressing well and were due for completion in June, but due to Covid-19 will be delayed until early 2021. The CN started their development and reviews with a comprehensive range of topics and is now left with the items that require cross discipline specialist discussions, e.g. with endocrinology, Ear Nose & Throat, surgery, anaesthesia. Given the busyness of all clinicians, it has been difficult in these challenging times to arrange mutually suitable meeting/discussion sessions. The proposed work will recommence when possible. • The CN is waiting on the publication of the Australian Cystic Fibrosis Standards of Care document. When available, the document will be reviewed for applicability and/or adaptations for NZ requirements. • PORT CF NZ, CFNZ and the Clinical Network are involved in two further projects; 1.)harmonising the registries internationally; and 2) determining the impact of Covid-19 on the CF population worldwide. Communication and updates are maintained through regular (international) videoconferencing meetings.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>PAEDIATRIC NEUROLOGY</p> <p>Established 2015</p> <p>www.starship.org.nz/neuronetwork/</p>	<p>Provide information to health professionals that informs best practice to enable delivery of appropriate standards of care</p>	<ul style="list-style-type: none"> • An Auckland Neurologist and Neurology Nurse Specialist has joined the CRG. • The CRG is seeking a new consumer representative due to the resignation of the Muscular Dystrophy Association representative • Due to Covid-19, management activities currently underway have been delayed. The delayed activities include a review of efficacy of Epilepsy passport and Stroke guidelines.
	<p>Enable nationally coordinated paediatric neurology services to achieve: consistency of care around New Zealand; improved linkages between families, primary, secondary, tertiary care and allied health; clear guidelines and resources to support diagnosis and management in primary and secondary care; in particular support children and youth who experience neurological conditions and their families</p>	<ul style="list-style-type: none"> • The main authors of the guidelines for Idiopathic Intracranial Hypertension and Care for Duchenne Muscular Dystrophy are reviewing these documents. • The CN is identifying working groups to develop guidelines and resources for Headache Management and Neonatal monitoring. • The CN continues to recognise the need to identify a Cognitive Behaviour Intervention for Tics Therapy (CBIT) guideline for children with Tourettes/TIC syndrome.
	<p>Assist health professionals (and their employing bodies) to meet their respective duties and obligations to ensure that health consumers receive the appropriate standard of care</p>	<ul style="list-style-type: none"> • Further Paediatric Epilepsy Training is planned in Auckland for October 2020 this; however, this is contingent on Covid-19 constraints. • Changes in roles and responsibilities of past organisers of the annual Neuromuscular Forum for Allied Health Professionals, plus an office change and Covid-19, has resulted in the postponement of the 2020 education forum. • The aim is to continue this education forum for allied health professionals working with Neuromuscular clients and an update on the 2021 forum will be advised in due course.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>PAEDIATRIC SLEEP SERVICES</p> <p>Established 2015</p> <p>www.starship.org.nz/sleepnetwork/</p>	<p>Development and implementation of quality improvement activities to enable clinicians/health professionals across the sector to deliver nationally coordinated, accessible and equitable paediatric sleep medicine services</p>	<ul style="list-style-type: none"> • CN CRG members are reviewing allocated sections for the revision of the NZ Guidelines of the Management of Sleep Disordered breathing (SDB). Remains a work in progress. • Revision and re-development of the CN website is a work in progress. • The project to develop an online learning tool for oximetry, developed in partnership with the Goodfellow Unit University of Auckland, is near completion. • The CN's CRG continues to contribute to the pathways for recognition and management of sleep disordered breathing in children with obesity as part of the Whānau Pakari initiative. • The CRG continues to work with the Health Promotion Agency around sleep health in paediatrics. • Sleep medicine clinicians will be involved with National Otorhinolaryngology (ORL) conference and workshop Oct 2020.
	<p>Assist health professionals (and their employing bodies) to meet their respective duties and obligations, so that best practice is promoted and health consumers receive the appropriate standard of care</p>	<ul style="list-style-type: none"> • Ear, Nose & Throat (ENT) surgical management <ul style="list-style-type: none"> - Research proposal to focus on understanding barriers to recognition and treatment of paediatric obstructive sleep apnoea (OSA) for Māori and Pacific Island children. The aim is to have outcomes that will guide how clinicians can best address current inequities. This is in the development stage. - Support provided to update Health Quality Safety Committee data and New Zealand Child & Youth Epidemiology Service (NZCYES) data on OSA hospitalisations and ORL surgical interventions by DHB. • Medical management <ul style="list-style-type: none"> - Ongoing review of Health Promotion Agency resources. - National survey circulated to paediatric clinical leads and ORL in all DHBs for feedback on national 3 centre hub and spoke model of care as outlined in briefing notes to MoH last year - Drive to improve the quality of increasing number of sleep studies undertaken on children in adult sleep laboratories and in private practice. - Involvement in the Starship Childrens Hospital Long Term Ventilation project as has national implications for resources, funding and planning of services. - Transition to adult sleep medicine services; guidelines on this to be included in the revision of the NZ Guidelines on Sleep Disordered Breathing document. - Ongoing review of relevant documents of sleep on KidsHealth website. • Ongoing development of consumer resources.
	<p>Develop and maintain the clinical network's infrastructure and embed activities, including research, to ensure sustainability and continuous quality improvement</p>	<ul style="list-style-type: none"> • Work in progress to replace the ENT representative on CRG, plus the need to replace the sleep specialist General Practitioner (GP) on the CRG. • Data regarding paediatric sleep patterns nationally is under review by CRG. • Explore the option of MoH incorporating questions on sleep in the B4 school check. CRG members involved in current MoH Well Child Tamariki Ora Service review with the aim to explore and speak to this need at relevant meetings of review MoH Committee. • Plan to construct feedback briefing to MoH on inequity of adenotonsillectomy in DHBs and on the survey about the hub and spoke model of national services. • Ongoing liaison after meeting with NZCYES to develop opportunities to extract data regarding paediatric sleep patterns nationally to inform ongoing work.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>TUBE FEEDING</p> <p>Established 2015</p> <p>www.starship.org.nz/tubefeedingnetwork</p>	<p>Provide resources and information to support best practice of clinical teams through development of resources</p> <p>Inform consumers and families about services and support access to information and resources</p> <p>Develop a learning system that informs and supports continuous quality improvement</p>	<ul style="list-style-type: none"> • This CN transitioned to a PSNZ Special Interest Group and ceased as a CN on 31 December 2019 • Resources remain available on the website with additional resources with a family focus pending
<p>INTERSEX</p> <p>Established August 2017</p> <p>Completion June 2020</p>	<p>Develop a definition of intersex for New Zealand</p> <p>Identify the data required to establish a national registry of intersex people</p> <p>Develop good practice guidelines</p> <p>Increase awareness of intersex health and people's related experiences through the development of targeted education programmes</p>	<ul style="list-style-type: none"> • A final report has been approved by the NZCYCN Governance Group and sent to MoH July 2020. • The report provides information on the agreed KPIs and further announcements will be shared through the MoH representatives and other stakeholders.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>PAEDIATRIC ALLERGY</p> <p>Established 2015</p> <p>www.starship.org.nz/allergynetwork</p>	<p>Develop and promote clear guidelines and resources for paediatric community, primary and secondary care health services that support timely diagnosis and effective management of allergies</p>	<p>Achieved:</p> <ul style="list-style-type: none"> i) Completed & uploaded in Food Allergy Guidelines (GLs) and Allergy CN website: <ul style="list-style-type: none"> • 'Food Challenge Guide' • 'Competencies for Food Challenges – medical & nursing' • 'Guide to Ongoing Care of Children/YP with Food Allergy' ii) 'Calcium needs for children with Cow's Milk Allergies ' updated. iii) 'Allergy Prevention: Introduction to recommendations in 'Nip Allergies in the Bub' approved; link added to the website; also supported by the Eczema CN. iv) Online Goodfellow module on Cow's Milk Allergy written by Allergy CN Clinical Lead v) Infant Formula Prescribing Algorithm completed. vi) Transition to GP care checklist completed. <p>Work in progress:</p> <ul style="list-style-type: none"> • Points (iv), (v) and (vi) above to be published on the website. • Development of a Soy infant formula FAQ tool, designed for use by GPs and parents. • National survey re primary-care access to dietitians. • Guidelines for penicillin allergy including diagnosis and 'de-labelling' and decision support tool. • Review and update of Environmental Allergy and Bee and Wasp Venom Allergy guidelines. • Allergy Myths and FAQ section for the website. • Link to Starship Childrens Hospital's Eosinophilic esophagitis (EoE) guidelines to be added once they are available. • The promotion of Medsafe authorisation for EpiPens in school/Early Childhood Education firstaid kits.
	<p>Develop and promote resources to help support families and young people with issues of self-management of food allergy</p>	<ul style="list-style-type: none"> • Resources developed by the Australasian Society of Clinical Immunology and Allergy (ASCI) are available to NZ families. Links are added to the Network's webpage following review by the CRG. • These resources are also referenced to the KidsHealth website. • An identified need to collate and rewrite the allergy information on the KidsHealth website; remains a work in progress. • The CRG also works with Allergy NZ.
	<p>Address inequities through promotion of allergy-related health workforce development</p>	<ul style="list-style-type: none"> • The CRG continue to identify and promote resources and support for training in primary care. • Preliminary planning has commenced to develop some brief video information clips for clinicians.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>CEREBRAL PALSY</p> <p>Approved June 2019 1st meeting Nov 2019</p> <p>www.starship.org.nz/health-professionals/cerebral-palsy-clinical-network</p>	<p>High level KPIs yet to be confirmed, the following are the agreed Objectives</p>	<ul style="list-style-type: none"> • An interim Clinical Lead has been confirmed and the CRG has been appointed. • Terms of Reference and work plan have been ratified and the first face-to-face meeting was held in November 2019.
	<p>Develop the Cerebral Palsy (CP) Clinical Network's (CN) infrastructure and embed activities to ensure sustainability post June 2020</p>	<ul style="list-style-type: none"> • Initial development has commenced on this and conversations are in progress with the newly formed Child Development and Disability CN
	<p>That the voices of children and young people CP and their families/whānau are heard and responded to in health-related activities</p>	<ul style="list-style-type: none"> • The CN has strong links with the Cerebral Palsy Society. A link to their video profiling the 'Voices of children and Young People' is on the website
	<p>The development and promotion of best practice recommendations and resources for paediatric health care professionals that supports timely diagnosis, early intervention and effective early management of Cerebral Palsy.</p> <p>Initial phase focuses on 0-2 years, workstreams agreed and activities include</p> <p>Design and develop improved transition for young people with CP from paediatric to adult health services.</p> <p>Create comprehensive understanding of key aspects of Selective Dorsal Rhizotomy and Intensives amongst DHBs and relevant Government Ministries.</p>	<p>Best Practice workstream</p> <ul style="list-style-type: none"> • Therapy checklist and early diagnostic pathway for diagnosis developed. • Now ready for clinical societies to give final feedback prior to publication on website. • Presented information at the PSNZ meeting in March on early detection of CP. <p>Transition workstream</p> <ul style="list-style-type: none"> • Collating recommendations from the international guidelines, and selected published literature, to produce summaries of action points for best practice. • Cerebral Palsy Youth Alliance are providing consumer feedback about what should be included in transition Selective. <p>Dorsal Rhizotomy (SDR) & Intensives workstream</p> <ul style="list-style-type: none"> • Completed flowchart of possible routes to obtain information and referral for SDR overseas; surveyed information on international websites. • A video conference was held with guests from Westmead Children's Hospital, Australia to discuss SDR with the CP and Child Development and Disability CNs. • Representatives from the 'Intensives' work stream engaged with Price Waterhouse Cooper who has developed an interim report. A presentation has been given to the parents/families and is open to others
	<p>Support the development of a sustainable pathway for the NZ Cerebral Palsy Register</p>	<ul style="list-style-type: none"> • Developed an infographic about the CP Register and presented on ethnic disparities for Māori with CP at inaugural Lunch and Learn (run by CD&D CN)
	<p>Establish a plan to enhance opportunities to provide education and networking across the sector (including primary healthcare) to provide the dissemination of national and international research and concepts.</p>	<ul style="list-style-type: none"> • Preliminary discussions on a planned, extended approach to workplan activities that will result in some activities to be implemented post March 2022. • Two CN members have been invited to join the implementation phase of the newly developed Australia and NZ Cerebral Palsy Strategy including development of priority areas and high level KPIs.

CLINICAL NETWORK	KPIs/HIGH LEVEL DELIVERABLES	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS
<p>CHILD DEVELOPMENT & DISABILITY</p> <p>Approved June 2019 1st meeting March 2020</p>	<p>Develop the CN infrastructure and embed activities to ensure sustainability</p>	<ul style="list-style-type: none"> • The challenges associated with bringing a widely diverse group of professionals and development diagnoses together during Covid-19 lockdown has been overcome and the workstreams have been identified and are now functioning well. • This CRG functions with a medical and allied health co-chair arrangement. • Work continues towards engagement between and merging the CP and Child Development and Disability CNs
	<p>Foster a culture of nationally coordinated Services across the continuum of care. Supporting health and education to meet the needs of children and young people who have developmental and disability related challenges and assist them towards achieving social independence.</p>	<ul style="list-style-type: none"> • In March 2020, a satellite day was held alongside the General Paediatric Update meeting and supported by MoH representative. The satellite day is being planned to be an annual event with the aim to raise the profile of the CN, its work and the needs of children and young people with developmental concerns and disabilities. • The first meeting with the Newborn CN has occurred. The aim is to establish a collaborative framework moving forward in relation to follow up practices for babies with high risk of disability. • Stakeholder feedback options are currently being investigated and include the education sector. • Collaboration with each of the MoH's regional Innovation Projects has occurred.
	<p>Develop Guidance documents and other resources to assist clinicians to identify challenges early and care for children with disability In line with best practice</p>	<ul style="list-style-type: none"> • 11 Workstreams have been identified. • Development of guidance documents for Down Syndrome are well underway. • The Attention deficit hyperactivity disorder (ADHD) workstream has had 2 zoom meetings and has agreed to develop resources to reduce the variation in acceptance criteria, assessment, and management. Scoping this work is underway. • "Lunch and Learn" sessions are being developed as an opportunity for the CRG to provide sector education and may help engage those professional not attached to DHBs These will be delivered online.
<p>NZCYCN WEBSITE</p> <p>A metric tool to profile access and update of the resources on the website. Established 2014</p>	<p>Consult with CRGs to ensure resources are developed and loaded in a user-friendly format and that ongoing liaison is maintained to retain currency</p>	<ul style="list-style-type: none"> • A formal, agreed process between the NZCYCN Governance Group and the Starship Childrens Hospital senior management team underpins the development, loading and reviews of resources for the website .
	<p>Site analytics are produced and distributed to all the CN's. This provide information on access of resources, which in turn, are used to informed current clinical practice</p>	<ul style="list-style-type: none"> • Metrics are produced that demonstrate access to the range of resources monthly and then tracked annually. This KPI metric provides valuable information to all the CNs and demonstrates the value of the shared information through the multidisciplinary, interested groups in NZ. Table 1. provides a snapshot of the progressive access of the website resources.

GOOD NEWS STORY

A summary of the Newborn CN's Clinical Reference Group's significant quality improvement achievement

The 2019 external review of Neonatal Intensive Care Units (NNIC Review) outlined several factors that influenced demand, length of stay and requirements for Neonatal Intensive Care Units (NICUs). The review identified opportunities to address capacity issues. The Ministry of Health (MoH) and District Health Boards (DHBs) agreed to develop a neonatal Transitional Care Plan for New Zealand (NZ) and the Newborn Clinical Network (CN) was asked to facilitate the project. A Project lead was appointed, there was comprehensive engagement from senior DHB's clinical and management personnel plus MoH representatives, all of which ensured there was good commitment to address the aims of the project.

Background

Neonatal care traditionally encompasses Intensive Care and Special Care provided within a neonatal unit. Some near term, and term babies, with short-term conditions may require care in either a neonatal unit or on the postnatal ward. Where this care occurs without separation from the mother this has been called Transitional care (TC). The NNIC Review identified that a more formal introduction of TC has the potential to reduce the current pressure on NICUs and Special Care Baby Units (SCBUs) in NZ.

Project development

Late 2019 a DHB, MoH and the Newborn CN working group was established and contributing information was obtained from other DHB staff and mothers who had recently given birth to babies with TC needs. Despite the short time frame, all parties demonstrated a high level of commitment to provide valuable feedback.

There was strong consensus from all parties of the critical importance of keeping mothers and their babies together in a whānau centred, dedicated TC space. It was agreed that enhancement of current TC should be delivered collaboratively, by neonatal and maternity teams resourced with safe staffing levels and supported by appropriate multidisciplinary teams (MDT), particularly Lactation Consultant (LC) and Social Worker



(SW) support. Additionally, and for the first time, Neonatal TC is described in the draft 2019 MoH Specialist Neonatal Inpatient and Community (Home Care) Services Tier Two Service Specification.

Across NZ DHBs, maternity and neonatal staff recommended a range of individualised solutions to address the scope of transitional care and within unit levels there was a degree of uniformity.

Location, size and space

A range of recommendations were made to address the location and size needed for the varying levels of NICU in DHBs and the proposed size requirement correlate well with current unit sizes. Some DHBs identified the need for more space and detailed work was produced that profiled current and future needs including capital investment requirements. The need for additional specific clinical and ancillary rooms required by DHBs to implement TC was proportionate to the footprint changes requested and this included a medication room or living room for whānau. The preferred bedroom type with strong agreement across DHB clinicians and consumers was for a single room that provided accommodation for parents/whānau and baby/pepi.

Model of care and staffing

The need for a collaborative model of care delivery, cognisant of safe staffing ratios for TC was emphasised in feedback from DHBs. This included the need for additional MDT support and

LC expertise was strongly flagged by DHBs. The feedback from the mothers ranked the need for LC support equally as their expectation for nursing and midwifery support.

Care of babies and postpartum mothers is within the scope of registered nurses and midwives; however, over the last 30 years changes in clinical practice in NZ has resulted in not all midwifery or nursing staff having the combined range of clinical expertise to care for babies with certain components of TC, such as nasogastric feeding in postnatal facilities or the expertise required to deliver maternal postpartum care. Therefore, to safely implement TC nationally, a collaborative model which includes neonatal nursing and midwifery expertise will be required to staff TC services to ensure delivery of consistently safe care for both the mother and baby. This to include a workforce development programme, care guidelines and supportive mentoring opportunities.

Key performances indicators (KPIs).

The DHBs provided feedback on a suite of KPIs that would enable safe delivery to be monitored, and to be able to measure neonatal transitional care outcomes. Additionally, the MoH signalled their KPI priorities to include evidence of NICU/SCBU reducing occupancy to 85% (or less) plus measures that provide evidence that equity is addressed.

Consumer feedback reported that enabling mothers to stay with their babies who have additional needs would make a huge difference to them. Standardised TC for this group of mothers and babies would promote the well-being of both the mother and baby and afford the best opportunity to establish breast feeding despite the challenges both mother and baby are experiencing.

Project result

This TC Project has been a significant activity for the Newborn CN and is an excellent example of how a CN can support quality improvement changes nationally and locally. The NICU / TC Report has been forwarded to the MoH and it is expected it will inform future clinical practice requirements in NZ.

NZCYCN Website. An overview of the number of resources viewed via web site page access

All the CNs receive a monthly, detailed update on the viewing access of their individual resources. This is an important metric

to track interest and can reflect seasonal variations.

Since April 2020, the seeking of resource information has been very consistent and the total is well above figures for previous years.

This period includes the major restrictions on population movement in NZ due to Covid-19.

Historically, June shows a decrease in web activity, but this has not been the case for June 2020. In addition to professionals seeking clinical information, the data also indicates that CNs have been busy updating resources and reconfiguring their web pages.

Table 2 shows the total number of page views since October 2018. Of note is the high number of page viewing in June 2020 that totalled 5,438.

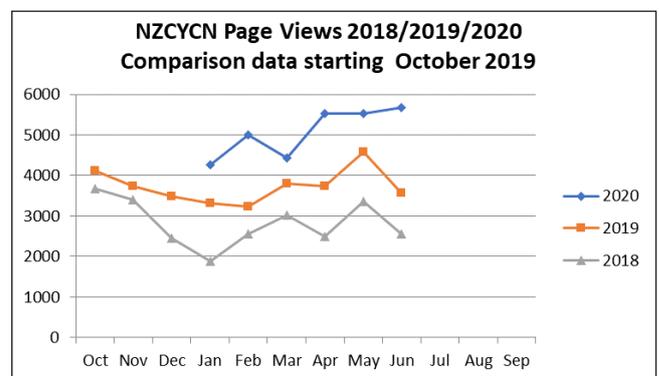


Table 2. Comparative overview since the NZCYCN web site commenced

Conclusion

This report outlines the achievements, work in progress and the continued support provided for the establishment, implementation and consolidation of the twelve (12) New Zealand (national) child and youth clinical networks.

The NZCYCN Governance Group continues to provide strategic oversight and guidance on the agreed activities of all the CNs. The Secretariat provides administrative support to manage the operational functions.

Like the rest of New Zealand, health services have been significantly affected by Covid-19. Some of this impact can be seen in the delays or modifications to each of the CNs' agreed work plans over the last four months of this reporting period.



Appendix 1: Governance Group Terms of Reference

New Zealand Child/Tamariki and Youth/Rangatahi Clinical Network Programme Governance Group⁶

Terms of Reference

1. SCOPE OF THE COMMITTEE

- 1.1 The New Zealand Child/Tamariki and Youth/Rangatahi Clinical Network (NZCYCN) programme's Governance Group (the Governance Group) is a Ministry of Health (MoH) Governance Group and is accountable to the MoH Chief Advisor, Child and Youth Health and the Group Manager of Integrated Service Design, Service Commissioning team. The MoH's Group Manager of Integrated Service Design, Service Commissioning, will collaborate with other business units within the MoH including the Health and Disability Services Policy Group.
- 1.2 The 2016 New Zealand Health Strategy, the New Zealand Health Strategy Roadmap of Actions and some of the Better Public Services Targets⁷ will help inform the functions of the Governance Group. Other child and youth reports and priorities identified by the sector will also inform NZCYCN functions and operations.
- 1.3 The functions of the Governance Group are:
 - to initiate the strategic development, implementation and review of clinical networks across the continuum of care for this population group
 - consider where clinical networks can make a difference for the population group
 - to report to the Minister (or other specified committees/advisors) on the strategic development, implementation and review of clinical networks for child/tamariki and youth/rangatahi health services
 - in partnership with all business units within the MoH, support the implementation and integration of child and youth clinical networks within District Health Boards (DHBs), primary care and other organisations who provide health services to this population group
 - to advise on any other matters related to child/tamariki and youth/rangatahi clinical networks as appropriate and within the resources available to the Governance Group.

2. DEFINITION

- 2.1 For the purpose of the Terms of Reference, the Governance Group considers the age bands of the population group are:
 - children/tamariki birth to 14 years inclusive
 - youth/rangatahi 15 to 18 years.
- 2.2 Defining strict criteria for age bands limits constructive network development. Therefore, the Governance Group

develops strong alliances with other key services including maternity services, mental health services and other relevant services and organisations. Some flexibility about the age at which children/tamariki transition to youth/rangatahi services and at which youth transition to adult services will be required as services should be delivered in a developmentally appropriate way. In general, young/rangatahi people would transition to adult services when they achieve social independence, noting that some young people remain socially dependent for extended periods of time.

3. COMPOSITION OF THE COMMITTEE

- 3.1 The Governance Group will have a minimum of ten and up to twelve members who will be recommended by PSNZ and appointed by the MoH representative. The Governance Group members will be known as New Zealand leaders across a range of child/tamariki and youth/rangatahi health service activities and will be broadly representative of a range of professional disciplines and organisations and geographic areas.
- 3.2 Collectively, the Governance Group will have knowledge of:
 - Quality improvement and risk management, in particular quality assurance in the health sector
 - Data and information gathering systems and analysis
 - Clinical epidemiology of the population group
 - Specialist academic requirements
 - Senior DHB service provision and management practices
 - Clinical experience across the range of primary, secondary and tertiary sectors for child/tamariki and youth/rangatahi health services
 - Māori child/tamariki and youth/rangatahi health matters
 - The health of Pasifika Populations
 - Consumer participation and representation.
- 3.3 The Governance Group will include a non-voting Ministry of Health representative.
- 3.4 The President of the PSNZ will be an automatic member of the Governance Group.
- 3.5 The Governance Group will co-opt specialist advice as required for specific topics.

4. TERMS AND CONDITIONS OF APPOINTMENT

- 4.1 All members of the Governance Group will demonstrate recognised expertise and leadership within child /tamariki and youth /rangatahi health services.

⁶ Reviewed and updated by the NZCYCN Advisory Group (renamed Governance Group March 2020) and MoH August 2017

⁷ <http://www.health.govt.nz/news-media/news-items/new-health-led-better-public-services-targets>

- 4.2 The terms of office will be for the duration of the contract between PSNZ and MOH and will be reviewed annually with regard to maintaining a mix of skills, experience and continuity to ensure the group meets the required composition for membership.
- 4.3 The appointment term will be for three years with the options of a further renewal of three years. All appointments are conditional on the term of the MoH contract with the PSNZ.
- 4.4 Any member of the Governance Group may resign as a member by advising the Chairperson in writing.
- 4.5 Any member may be removed from the Governance Group at any time on the basis of discussions with the Governance Group Chair, representative of the Ministry of Health and on advice from the PSNZ Executive.
- 4.6 The Governance Group, in consultation with the MoH Chief Advisor – Child and Youth Health, may from time to time alter or reconstitute the Governance Group for the purpose of decreasing or increasing the membership or filling vacancies.
- 4.7 Governance Group membership will follow an open expression of interest process with the appointment(s) made by a small Governance Group Executive team⁸.

5. CHAIRPERSON

- 5.1 The Ministry of Health's Chief Advisor, Child and Youth Health and the PSNZ President will appoint a member of the Governance Group to be its Chair. The Chairperson will preside at every meeting of the Governance Group at which they are present.
- 5.2 The Governance Group will appoint one of its members as the Deputy Chairperson.
- 5.3 The appointment term will be for three years with the option of a further renewal of three years. All appointments are conditional on the term of the MoH contract with the PSNZ.
- 5.4 The Chairperson is the Governance Group's spokesperson on all external requests for information and in particular request from the media.

6. DUTIES AND RESPONSIBILITIES OF A MEMBER

- 6.1 As an independent Committee, the Governance Group has an obligation to conduct its affairs in an open and ethical manner. The Governance Group has a duty to operate in an effective manner within the parameters of its functions as set out in its Terms of Reference.
- 6.2 The Governance Group members should have a commitment to work to improve health services across New Zealand for the greater good of children and youth.
- 6.3 There is an expectation that members will make every effort to attend all Governance Group meetings and devote sufficient time to become familiar with the affairs of the Governance Group and the wider health service in which it operates.
- 6.4 Members have a duty to act responsibly with regard to the effective and efficient administration of the Governance Group and use of contracted funds.

- 6.5 The maintenance of confidentiality is crucial to the functioning of the Governance Group and members must note the statutory requirements in section 59E (6) of the Privacy Act, which prevents disclosure of information of the kind described in clause 3 of schedule 5 of the Act. 26.3. Under this clause, information means any information that is personal information within the meaning of section 2(1) of the Privacy Act 1993.
- 6.6 Members must be aware that information and matters discussed at Governance Group meetings are confidential and must not be shared outside the Group's meetings.

7. CONFLICTS OF INTEREST

- 7.1 Members must perform their functions in good faith, honesty and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest.
- 7.2 Members must attend meetings and undertake Governance Group activities as independent persons responsible to the Governance Group as a whole. Members are not appointed as representatives of professional organisations and groups. The Governance Group should not, therefore, assume that a particular group's interests have been considered because a member is associated with a particular group.
- 7.3 When members believe they have a conflict of interest on a subject that will prevent them reaching an impartial decision or understanding an activity with the Governance Group's functions, they must declare that conflict of interest and withdraw themselves from discussion and/or activity.
- 7.4 All members will be required to complete a conflict of interest declaration on appointment to the Governance Group. At each meeting members will be asked to confirm or amend their declaration.

8. FEES AND ALLOWANCES

- 8.1 There is no payment for meeting preparation or participation in teleconferences.
- 8.2 DHB employees will be funded by their employing DHB and will not receive any funding for attendance however, reasonable travel expenses will be paid.
- 8.3 Non-DHB members will be paid the standard MoH daily attendance rate per the Cabinet Office Circular (CO (12) 6) the fees framework for members appointed to bodies in which the Crown has an interest, plus travel costs.

9. MEETINGS

- 9.1 Meetings will be six to eight weekly. Actual and reasonable expenses for activities required by the Governance Group of its members (e.g. travel, accommodation) will be met from the Governance Group's budget provided prior approval is received.
- 9.2 The timing of meetings will be determined by the tasks the Governance Group is obliged to fulfil and as part of its work programme to be agreed with the MoH Chief Advisor – Child and Youth Health and the Group Manager, Integrated Service

⁸ Composition of the Advisory Group Executive Team; Advisory Group Chair, Deputy Chair nominated from the Advisory Group, Ministry of Health representative and PSNZ CEO

Design, Service Commissioning.

- 9.3 Two to three face-to-face meetings will be held annually with audio conference calls and/or video conferencing at six to eight weekly.
- 9.4 A meeting quorum will be 50% + 1 of the Governance Group membership.

10. PERFORMANCE MEASURES

10.1 The Governance Group will provide relevant and timely advice to the MoH Chief Advisor, Child and Youth Health and the Child and Family Programmes, Integrated Service Design, Service Commissioning team, based on research, analysis and consultation with relevant groups and organisations.

10.2 The Governance Group must:

- agree in advance to a work programme developed in consultation with the MoH Chief Advisor - Child and Youth Health and the Group Manager, Integrated Service Design, Service Commissioning
- achieve its work programme
- stay within its allocated budget
- require clinical networks, or any other group, to comply with appropriate systems and processes to manage sensitive data collection⁹.

10.3 In carrying out its functions, the Governance Group must ensure that:

- appropriate consultation has occurred when developing a methodology and subsequently disseminating findings
- any recommendations are developed in the context of available evidence and resources
- a Risk Register is developed and regularly updated
- any advice and recommendations comply with the laws of New Zealand

11. TREATY OF WAITANGI

11.1 The Governance Group is expected to undertake its tasks in a manner consistent with the principles of the Treaty of Waitangi.

12. REPORTING REQUIREMENTS

12.1 The Governance Group is required to keep minutes of all committee meetings that outline the issues discussed and includes a clear record of any decisions re recommendations made. These are to be distributed by two weeks post meeting.

12.2 The Governance Group is required to prepare an annual report to the Group Manager Integrated Service Design, Service Commissioning, the Ministry of Health setting out its activities and comparing its performance to its agreed work programme and summarising any advice that is given in carrying out its contracted role.

12.3 Contract Specifications will determine reporting requirements.

13. SERVICING THE COMMITTEE

13.1 Administrative support will be provided by PSNZ. This will be funded under the PSNZ and MoH contract for services.

14. WORK PLAN

14.1 The Governance Group must develop strategic plans and methodologies to develop, implement and evaluate the NZCYCN programme. Work to include:

- advising on the infrastructures required to support the New Zealand Child and Youth Clinical Network programme development, implementation and sustainability
- providing support for the New Zealand Child and Youth Epidemiology Service and KidsHealth Parent Information Service
- liaison with relevant non-Government organisations and education services.

14.2 A work plan will be developed and or updated each year during the period of the contract.

⁹ <http://www.paediatrics.org.nz/files/2015%20Documents/PSNZ%20Clinical%20Information%20Policy%20and%20Position%20Statement%20July%202015.pdf>

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

MEMBERSHIP LIST AT JUNE 2020:

Richard Aickin	Chair, Governance Group; Emergency Medicine Specialist, Starship Children's Hospital, ADHB (2010, Chair from July 2014)
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)
Cameron Grant	Paediatrician, Starship Children's Health, Professor in Paediatrics, The University of Auckland (6/2019)
Fiona Graham	Occupational Therapist; Senior Lecturer, Rehabilitation Teaching & Research Unit, University of Otago (11/2017)
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).
Tim Jelleyman	Child Health Advisor, Ministry of Health (2/2020)
Bridgette Farrant	Adolescent Physician, Society of Youth Health Professional Aotearoa NZ (SYHPANZ) Representative (June 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	P/T 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. Role changed at HBDHB, resigned 6/2014
Nick Baker	Clinical Director, Child Health, Nelson/Marlborough DHB. Resigned August 2013 due to change in role at NMDHB
Danah Cadman	Interim General Manager, Starship, ADHB. Seconded for 6-month period from 2013, resigned 6/2014 due to change in role
Barry Taylor	Deputy Chair, Professor of Paediatrics & Child Health, Otago University. Resigned 11/2013
Vili Sotutu	Paediatrician, Southern DHB; 2014 - 12/2015. Resignation due to role change
David Newman	Paediatrician and past PSNZ President (2015 – 2017)
John Forman	Executive Director, NZORD, Appointed 2010, Resigned December 2014
Glenn Doherty	GP & Medical Director, Tongan Health Society Inc., Auckland (10/14 - 2016)
Kate Russell	Consumer Representative, Chief Executive Canterbury Medical Research Foundation NZ Brain Research Institute. (11/2014 - 2017)
Gary Tonkin	MoH, Senior Portfolio Manager 2014 – 8/2015
Kate Chong	MoH National Programme Manager, Child & Family Programmes, (3/16–3/17)
Chris Moyes	Paediatrician, Bay of Plenty DHB 2010 – 6 /2018
Laura Warwick	Advisor, Child and Family Programmes, Integrated Service Design, Service Commissioning, MoH. (March 2017 – 8/2018)
Rosemary Marks	Paediatrician, ADHB (Past PSNZ President & inaugural Governance Group chair for 6 yrs, member of the Governance Group; 2010 – 12/2018)
Jon Buchan	Portfolio Manager, Whanganui DHB (9/2014 – 12/2018). Change in role
Julie Chambers	Senior Advisor, Child Injury Prevention, ADHB (2010-08/2018)
Dawn Elder	Professor and HOD, Department of Paediatrics and Child Health, Otago University, Wellington School of Medicine (2/2014 – 1/2019). Changes in role responsibilities
Pat Tuohy	Chief Advisor, Child and Youth Services, MoH. Retired from MoH 31/7/2019 (2010- 7/2019).
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)
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)

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