

# ANNUAL REPORT

1 JULY 2017 – 30 JUNE 2018

## NEW ZEALAND CHILD AND YOUTH CLINICAL NETWORK



# Abbreviations and Glossary

AG	Advisory Group: The governance group of the NZCYCN programme
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 Advisory 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
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
MoH	Ministry of Health
MoU	Memorandum of Understanding: Formal agreement between key stakeholders and/or organisations whose practice links with and/or supports the NZCYCN programme
MDT	Multidisciplinary teams of health professionals
NZ	New Zealand
NZCYCN	The New Zealand Child and Youth Clinical Network Programme; a quality improvement initiative
NZCYES	The New Zealand Child and Youth Epidemiology Service <a href="http://dnmeds.otago.ac.nz/departments/womens/paediatrics/research/nzcyes/dhb.html">http://dnmeds.otago.ac.nz/departments/womens/paediatrics/research/nzcyes/dhb.html</a>
NGO	Non-Government organisation. Primary and community care health organisations
PSNZ	The Paediatric Society of New Zealand <a href="https://www.paediatrics.org.nz/">https://www.paediatrics.org.nz/</a>
QI	Quality Improvement: the process through which a planned approach supports changes in practice, based on best practice recommendations and/or guidelines that can be translated to front line practice. Integral to this process is the need to have a plan that supports change and the provision of ongoing education
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

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# Chair's Message



The seventh annual report of the New Zealand Child and Youth Clinical Network Programme provides a summary of the extensive achievements and ongoing work of the twelve networks currently established under this contract. The networks are diverse in focus and composition, reflecting priorities which have been presented to the Advisory Group by health professionals and the Ministry of Health.

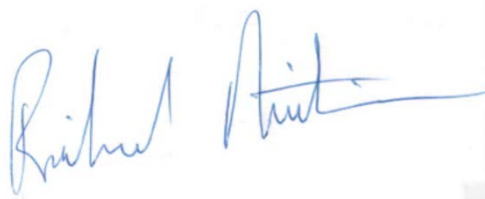
The success of each network is highly dependent on the energy and commitment of the Chair and members of that network's Clinical Reference Group (CRG). Those individuals have taken on significant amounts of work for the networks on top of their usual professional responsibilities, largely because of their commitment to improving the quality and accessibility of healthcare for NZ children. The work programme in each network is set by the CRG based on issues which have recognised problems with inconsistent clinical approaches, outcomes, access to expertise, and unmet need. I believe that the New Zealand Child Youth Clinical Networks programme continues to provide an effective and efficient way to address many of these problems at remarkably low cost.

The ongoing challenges for the programme include our capacity for establishing new networks and the process to transition older networks to "business as usual" to enable resources to be invested in new work. More recent networks have been established with an explicit timeframe to achieve an agreed set of goals rather than the previous open ended plans. The newer project style approach is likely to allow us to remain responsive to new priorities for network development as these arise.

Our Advisory Group (AG) has seen a regular refreshment of membership as individuals have stepped down due to retirement and changes in their availability. I believe that we have been able to maintain a good breadth of representation across the spectrum of health professionals, cultural and geographic diversity and consumer representation.

The support of the Ministry of Health members attending the AG is invaluable to ensure good communication and navigation of the NZ Health system by the group. I particularly thank Dr Pat Tuohy for his continued and consistently helpful advice and contribution to discussions.

I am always happy to be contacted for any questions or discussion about the New Zealand Child and Youth Network programme.

A handwritten signature in blue ink, reading "Richard Aickin".

**Dr Richard Aickin FRACP FACEM**  
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Chair, Advisory Group NZCYCN  
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# The Seventh Annual Report for the Programme

## First published report

### INTRODUCTION

In 2008 the Paediatric Society of New Zealand (PSNZ) discussed with the Ministry of Health (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 national network development programme.

### WHY DEVELOP NATIONAL CLINICAL NETWORKS?

A range of international papers describe<sup>1</sup> the benefits and challenges of clinical networks (CNs). 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 model 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 NZCYCN programme was created.

### ABOUT THE NZCYCN PROGRAMME

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

NZ Child and Youth Epidemiology Service and the KidsHealth<sup>2</sup> website link with and provide support to each of the CNs.

### STRATEGIC DOCUMENTS

The documents that informed and supported the programme's development include, but are not limited to:

- NZ Government's 'Better Public Service (BPS) Targets'<sup>3</sup>. In particular targets 2 and 3.
- MoH's (2016) Health Strategy – Future Directions and its partner document Roadmap of Actions.
- Health Funding Authority and PSNZ 1998 Report, 'Through the Eyes of a Child' and a 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'<sup>4,5</sup>.
- The Evaluation Report<sup>6</sup> on the Development and Implementation of the New Zealand Child and Youth Clinical Network Programme (2017).

### GOVERNANCE AND ACCOUNTABILITY

The contract required the appointment of an Advisory Group to provide governance and support the contract's operations. The MoH approve the appointment of an Advisory Group Chair and membership of the Advisory 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 Advisory Group membership in Appendix 1).

Up to three face-to-face meetings are held annually, interspersed by six-weekly conference calls. One of the face-to-face meetings is a shared work-shop between the Advisory Group, the CN leaders and 'facilitators.' 'Facilitators' are expert clinicians who provide additional support to each CN to progress the subspecialty's 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.

An independent, formal evaluation report on the NZCYCN Programme's contracted deliverables has been completed and records that the contractual requirements are being met. The programme has established links with a 'like type' UK programme to compare and contrast this programme to other models. An outcome of this link resulted in the academic advisor of the UK's "Partners in Paediatric", programme visiting New Zealand. An informal academic overview of the NZ programme was positive<sup>7</sup>.

1 Reference NHS (1999) – Scottish Executive Guidance. 12 Core Principles of MCN. 2. [www.kidshealth.org.nz/](http://www.kidshealth.org.nz/). 3. [www.health.govt.nz/publication/delivering-better-public-services-good-start-life](http://www.health.govt.nz/publication/delivering-better-public-services-good-start-life). 4. <http://adc.bmj.com/content/98/11/843>. 5. 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. 6. The full report can be viewed at [www.paediatrics.org.nz/](http://www.paediatrics.org.nz/). 7. Cropper, S. Article in NZCYCN Programme's March 2017 CYNet publication [www.paediatrics.org.nz/](http://www.paediatrics.org.nz/).

## SECTOR CONSULTATION AND COMMUNICATION





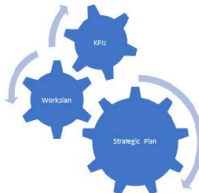


To ensure the voice of NZ's child and youth health's multidisciplinary (MDT) clinicians was heard, in mid-2011 four regional meetings attended by 175 child and youth health professionals was held. The themes developed at these meetings informed the programme's core aim which was to develop a successful 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; improve metrics to demonstrate the networks' quality improvement activities and changes in practice. These activities are profiled in each network's work and strategic plans.

## WHAT ARE THE NZCYCN PROGRAMME'S ACHIEVEMENTS AND WORKS IN PROGRESS?

Below is a summary of developments, followed by a profile of the 12 high level 'work-in-progress' or achievements, aligned to the 2016 Ministry of Health Strategic Direction and Roadmap of Action.

### 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:

<b>12</b>	12 subspecialty Clinical Networks (CN) established: Child Protection, Palliative Care, Diabetes, Eczema, Newborn, Gastroenterology, Cystic Fibrosis, Neurology, Sleep Medicine, Tube Feeding, Allergy and Intersex.
	The first CN was established late 2010 and by early 2018 12 CNs were in varying phases of development and consolidation.
	Annually, two face-to-face meetings and approximately six weekly conference call or Zoom meetings are held.
	Over 200 website resources/best practice recommendations/links with related websites established, all with review dates have been developed <a href="http://www.starship.org.nz/for-healthprofessionals/new-zealand-child-and-youth-clinical-networks/">www.starship.org.nz/for-healthprofessionals/new-zealand-child-and-youth-clinical-networks/</a> Resources are on the Starship Child Health website. Online publication is supported by the Starship management team.
	A biannual publication of the programme's newsletter CYNet ( <a href="http://www.paediatrics.org.nz">www.paediatrics.org.nz</a> ) profiles activities and new developments.
	All CNs have a nominated clinical leader and a MDT 'Clinical Reference Group' (CRG) that agrees the deliverables for that CN's workplan, key performance indicators (KPIs) and their Strategic Plan.
	All CNs provide quarterly reports on KPIs and workplan achievements.
<b>MDT</b>	At early 2018, a total of 180 MDT members had, or were, contributing to the various CN's CRGs.
	Contracted 'Facilitator' support is provided to each CN to assist the leader and CRG with activities.
<b>50%</b>	50% of the subspecialty CNs have been developed at the request of MoH.
	Established formal links with the 23 PSNZ Special Interest Groups (SIGs), KidsHealth, NZ Child and Youth Epidemiology Service, regional health alliance groups, RNZ Plunket Inc, Telemedicine Trust (was TelePaediatrics), National Child Health Managers & DHB Portfolio management groups, the Violence Intervention Programme and a range of other professional organisations.
	Established links with international network organisations and/or subspecialty clinical networks. Six formal memorandums of understanding/agreements with horizontal/networks/organisations established.



# The NZCYCN Programme supports the Ministry of Health's Strategic Direction and Roadmap for Action

The NZCYCN programme is a quality improvement tool designed to promote, and support, positive change in health service delivery<sup>8</sup>.

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:

- People-Powered (PP)
- Closer to Home (CH)
- Value and High Performance (VHP)
- One Team (OT)
- Smart Systems (SS)



The 12 NZCYCN networks are noted below. Further information can be viewed on the Starship Children's Hospital website via each CN's dedicated web page.

<a href="http://www.starship.org.nz/for-health-professionals/">www.starship.org.nz/for-health-professionals/</a>
Child Protection
<a href="http://www.starship.org.nz/childprotectnetwork">www.starship.org.nz/childprotectnetwork</a>
Palliative Care
<a href="http://www.starship.org.nz/palliativecarenetwork">www.starship.org.nz/palliativecarenetwork</a>
Diabetes
<a href="http://www.starship.org.nz/diabetesnetwork">www.starship.org.nz/diabetesnetwork</a>
Eczema
<a href="http://www.starship.org.nz/eczemanetwork">www.starship.org.nz/eczemanetwork</a>
Newborn
<a href="http://www.starship.org.nz/newbornnetwork">www.starship.org.nz/newbornnetwork</a>
Gastroenterology
<a href="http://www.starship.org.nz/gastroenterologynetwork">www.starship.org.nz/gastroenterologynetwork</a>
Cystic Fibrosis
<a href="http://www.starship.org.nz/cysticfibrosisnetwork">www.starship.org.nz/cysticfibrosisnetwork</a>
Neurology
<a href="http://www.starship.org.nz/neuronetwork/">www.starship.org.nz/neuronetwork/</a>
Sleep Medicine
<a href="http://www.starship.org.nz/sleepnetwork/">www.starship.org.nz/sleepnetwork/</a>
Tube Feeding
<a href="http://www.starship.org.nz/tubefeedingnetwork/">www.starship.org.nz/tubefeedingnetwork/</a>
Allergy
<a href="http://www.starship.org.nz/allergynetwork">www.starship.org.nz/allergynetwork</a>
Intersex (under development)

The following table provides examples of outcomes and 'work(s) in progress' of each CN, with alignment to each of the five themes in the MoH's Road Map for Action. Three example case studies on some CN successes are profiled later in the report.



8 New Zealand Health Strategy Roadmap of Actions. 2016. NZ Government, Wellington.

**TABLE 1. NZCYCN PROGRAMME'S ACHIEVEMENTS OR WORK(S) IN PROGRESS, ALIGNED TO THE 2016 MOH: HEALTH STRATEGY - ROAD MAP FOR ACTION<sup>10</sup>**

Table one outlines some of the achievements of the CNs within the NZCYCN programme for the period ending 30 June 2018.

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>CHILD PROTECTION</b> Established 2011 <a href="http://www.starship.org.nz/childprotectnetwork">www.starship.org.nz/childprotectnetwork</a>	An annual Child Protection Satellite Day for multidisciplinary team members of this CN is held. The day is well-attended and presentations include practical information for frontline clinicians, policy updates and research findings. Attendees are multi-disciplinary professional and include Nurses, Paediatricians, DHB Violence Intervention Programme Coordinators, Social Workers and others. Evaluation(s) of the day are positive.			√	√	
	Memorandum of Understanding (MoU) between DHBs, Child Youth and Family and Police: All DHBs have signed the MoU. The four schedules are: Schedule 1: Children admitted to hospital with suspected or confirmed abuse or neglect. Schedule 2: Child, Youth And Family/District Health Board Liaison Social Worker. Schedule 3: Neglect of Medical Care Guideline. Schedule 4: Joint Standard Operating Procedures for Children and Young Persons in Clandestine Laboratories..			√	√	
	A list of Paediatricians in each DHB provides an initial contact for first point of contact on child protection matters. A survey of paediatricians' views about working in child protection has been completed and has provided information to inform planning of child protection service provision for DHBs of all sizes.		√			
<b>PAEDIATRIC PALLIATIVE CARE SERVICES</b> Established. 2012 <a href="http://www.starship.org.nz/palliativecarenetwork">www.starship.org.nz/palliativecarenetwork</a>	Comprehensive 'End of Life Care Guidelines' for Paediatric Palliative Care have been developed and used by clinicians nationally and internationally. A review was commissioned to ascertain the need to update these – affirmed as required as a number of new guidelines have been published since the initial guidelines were developed. The indication is there are several areas that require updates and/or new topics developed.	√	√	√	√	√
	An advanced care planning survey is underway for Clinical Directors of Paediatric Services nationally to complete. This will inform the CN of current clinical practice to assess services practice nationally.	√	√	√	√	√
	The monthly video conference education programme continues with more than ten sites for each forum. Feedback is positive and the programme is also being used by rural sector RNs. Refer to story on page 14.		√	√	√	√

<sup>10</sup> <http://www.health.govt.nz/new-zealand-health-system/new-zealand-health-strategy-roadmap-actions-2016>



CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>CHILDREN AND YOUNG PEOPLE WITH DIABETES</b> Established 2012 <a href="http://www.starship.org.nz/diabetesnetwork">www.starship.org.nz/diabetesnetwork</a>	Update of guidelines completed for 'away from home camps' for children with diabetes. It is proposed to conduct a consumer survey targeting resourcing and perception of the complexities of camps and/or overnight outings to inform the revision of the guidelines.	√		√		
	<ul style="list-style-type: none"> <li>A MoU with the Aotearoa College of Diabetes Nurses signed in July 2015. Collaborative working relationships are in place to develop and share resources.</li> <li>A professional group in Victoria, Australia have shared some of their nursing/ school resources which have been loaded on the website.</li> </ul>	√	√	√	√	√
	The Dunedin Paediatric Diabetes team surveyed and reviewed Insulin pump initiation practices in NZ, including preparation, aftercare and follow-up of individuals commencing pump therapy. A manuscript based on this work has been submitted to the 'Journal of Paediatric and Child Health 2017'.			√	√	
	A workforce survey was completed in 2012 and published in the New Zealand Medical Journal (Jefferies et al NZMJ 30 October 2015, Vol 128 No 1424). The survey has been repeated in 2016, in conjunction with an Australasian-wide survey being undertaken by the Australasian Paediatric Endocrine Group (APEG) and the results have been submitted for publication.			√	√	
	A number of resources have been developed and are available on CN's webpage and KidsHealth website for family information.	√	√	√	√	√
<b>TREATMENT OF CHILDHOOD ECZEMA</b> Established 2012 <a href="http://www.starship.org.nz/eczemanetwork">www.starship.org.nz/eczemanetwork</a>	Recommendations from the review of eczema referral pathways, working group discussions and clinical partnerships are able to be followed/shared as relevant and appropriate. Refer to story on page 13.	√	√	√	√	√
	Number of resources developed and available on Starship and KidsHealth websites including <ul style="list-style-type: none"> <li>Pictorial Eczema Care Plan loaded on the CN's webpage</li> <li>Video developed for KidsHealth on bathing and application of ointments/creams. Excellent feedback on this resource</li> <li>The CN is currently reviewing and updating website pages.</li> </ul>	√	√	√	√	√
	Numerous articles and research findings have helped support and improve regular communication with the wider DHB network. Feedback has been positive; this in turn has prompted communication from the extended membership group regarding clinical questions or enquiries about more resources. These enquiries are useful to reinforce best practice, to identify resources or provide support and often underpin issues the CRG has already identified. Additionally, the network has had enquiries from clinicians wanting to join the mailing list indicating this information is being disseminated widely.	√	√	√	√	√
	Teaching/education includes presentations to regional PHN updates; rural GP conference, GP registrars, support for RN education days by Pharmac and other organisations. Development of 'Training and Education' page on website with links to resources for GPs and allied health professionals.	√	√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>NEWBORN</b> Established 2013 <a href="http://www.starship.org.nz/newbornnetwork">www.starship.org.nz/newbornnetwork</a>	Resource recommendations developed for: Neonatal Subgaleal Haemorrhage Practice Recommendations; Practice Recommendation for Oxygen Saturation Targets for Newborns cared for in Neonatal Units, NZ; <a href="#">Consensus Statement for Screening for Retinopathy of Prematurity</a> ; Practice Recommendation for the Treatment of Hypoglycaemia with Dextrose Gel; <a href="#">Consensus Statement for Treatment of Neonatal Encephalopathy</a> ; <a href="#">Guidelines for the Inter-hospital Transfer of Neonatal Infants</a> .		√	√	√	√
	Working with MoH on two projects <ul style="list-style-type: none"> <li>a national neonatal intensive care unit review</li> <li>involved in reviewing the service specifications.</li> </ul>		√	√	√	√
	In collaboration with NZCOM developing recommendations for managing hypernatraemia dehydration in breast-fed babies.		√	√	√	√
<b>PAEDIATRIC GASTROENTEROLOGY SERVICES</b> Established 2013 <a href="http://www.starship.org.nz/gastroenterologynetwork">www.starship.org.nz/gastroenterologynetwork</a>	A new Coeliac disease diagnostic pathway has been developed for the Greater Auckland Region reducing clinical dependence on endoscopy services. The pathway models the international ESPGHAN guidelines using gastroenterologist reviewed blood assays rather than endoscopically obtained biopsies.			√	√	√
	Work has commenced to provide nationally aligned resources for families managing Eosinophilic Oesophagitis. This workgroup will engage with GPs in order to progress.	√	√	√	√	√
	Opportunities to engage with the health pathways group are being identified across all workstreams.	√	√	√	√	√
	A Jaundiced Baby Referral Pathway has been developed with input from multiple organisations and is located on the CN's webpage: Refer to story on page 14..  Opportunities have been identified to continue to raise awareness and early diagnosis of conjugated jaundice including midwife study days and conference(s) plus GP newsletter.	√	√	√	√	√
	Links with other organisations include: <ul style="list-style-type: none"> <li>The CRG is active on several Pharmac committees to advocate for paediatric gastroenterology patient needs</li> <li>A MoU between the CN and the endoscopy working group to provide specific paediatric advice.</li> </ul>		√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>CYSTIC FIBROSIS</b> Established 2014 <a href="http://www.starship.org.nz/cysticfibrosisnetwork/">www.starship.org.nz/cysticfibrosisnetwork/</a>	The group has developed resources to support family understanding and provide practical advice alongside the medical guidelines. Resources developed have had considerable consumer input and have started with issues deemed the most important in day-to-day care throughout childhood and the transition to adult care.	√	√	√	√	√
	Sections regarding guideline management of assessment and treatment addressing the multitude of issues faced by children and youth with Cystic Fibrosis have been developed and loaded on the 'Clinical Guidelines' webpage. This section has had the second most 'hits' compared to all the networks currently represented on the website. The aim is to complete all the guideline sections in the first Quarter of 2019.					
	'Nutrition' and 'Physiotherapy' sections of the Guideline have been developed by a trans-Tasman alliance of clinicians and allied health professional with expertise in the care of cystic fibrosis.	√	√	√	√	√
	To progress the guideline development more quickly and address the challenge of getting the CRG members together regularly (given workloads and time conflicts), the CRG has moved to having bi-monthly Zoom meetings, with one annual face-to-face meeting.					
<b>PAEDIATRIC NEUROLOGY</b> Established 2015 <a href="http://www.starship.org.nz/neuronetwork/">www.starship.org.nz/neuronetwork/</a>	The CRG includes two representatives from Cystic Fibrosis NZ which gives an integrated approach to care and provides a strong consumer voice.	√		√	√	
	Number of resources developed (including epilepsy and neuromuscular), shared nationally and available on the CN's webpage and KidsHealth website. Recent resources include Microcephaly and Duchenne's Muscular Dystrophy Guidelines for Steroid use and Patient information leaflets for Epilepsy.	√	√	√	√	√
<b>PAEDIATRIC SLEEP SERVICES</b> Established 2015 <a href="http://www.starship.org.nz/sleepnetwork/">www.starship.org.nz/sleepnetwork/</a>	Considerable support provided for the Paediatric Epilepsy Training (PET) 1,2 & 3 training of NZ Paediatric Neurologists and Paediatricians held in Auckland and Wellington.			√	√	√
	The CN's webpage includes comprehensive and abbreviated guidelines and has been viewed 110-140 times per month since March 2018.	√	√	√		√
	CRG members continue to disseminate the guidelines, give presentations on oximetry and other sleep related issues across the country to a range of health professionals (including GPs) at national and international sleep-related meetings/conferences.		√	√	√	√
	The KidsHealth information leaflet on Melatonin has been completed.	√	√	√	√	√
	Data from an audit on using paediatric sleep questionnaire in plastic surgery clinics was the subject of a poster presentation at a maxillofacial conference.			√	√	√
	The 2013 National Sleep Medicine Facilities survey has been reviewed, re-survey completed and results analysed. Presentation to be made at PSNZ Annual Scientific meeting in November 2018.	√	√	√	√	√
	A programme of oximetry workshops in DHBs has been completed. Additional workshops to be held upon request		√	√	√	√
	Responders to a previous oximetry interpretation study are being contacted re taking part in a quality project with determined criteria based on current guidelines.		√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>TUBE FEEDING</b> Established 2015 <a href="http://www.starship.org.nz/tubefeedingnetwork">www.starship.org.nz/tubefeedingnetwork</a>	Progressing guideline and resource development with input from all disciplines; medical, nursing, dietetic, occupational therapy, speech and language therapy and psychology • Numerous new speech language therapist resources, clinician-specific resources under development • A parental checklist for going home with a feeding tube has been developed and finalised.	✓	✓	✓	✓	✓
	A survey of the 20 DHBs has been conducted (aligned to the 2013 survey) and will assist in estimating the number of children receiving prolonged tube feeding nationwide. This will continue to inform intervention strategies.		✓	✓	✓	✓
	Presentation and updates to the Health Select Committee in regard to a petition that Tube Feeding NZ put forward about their concern about access to intensive weaning services.			✓	✓	✓
	The consumer representative has developed a survey to enable consumers to identify how families access information and what they need, shared widely both electronically in hard copy. Results have been analysed and a report drafted.	✓	✓	✓	✓	✓
<b>PAEDIATRIC ALLERGY</b> Established 2015 <a href="http://www.starship.org.nz/allergynetwork">www.starship.org.nz/allergynetwork</a>	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 have been developed into actions in the work plan.	✓	✓	✓	✓	
	The CN's webpage includes guidelines for; Allergy Prevention; Anaphylaxis; Environmental Allergy; Food Allergy; Family Information; Training & Resources for Health Professionals, Venom Allergy. Allergy Testing including Food Challenges, Immunotherapy for environmental allergies. Drug Allergy guidelines remain a work-in-progress. Information and resources can also be accessed via the KidsHealth website. Data from the websites indicate that children and young people with allergies and their families are accessing the information and resources.	✓	✓	✓	✓	✓
<b>INTERSEX</b> Established August 2017 This is a specific two (2) year project Webpage under development	Established at the request of MoH to address biological intersex/DSD treatment issues for children and youth; 0 to 18 years. The CN is a partnership between consumers and clinical leaders to improve health practices, systems and approaches for intersex children and youth. Along with the ToR the deliverables for the project have been agreed. Key deliverables for phase one include: • developing a definition of intersex for NZ • completing a stocktake of current educational resources and programmes relevant for health workforce, intersex children, young people and their whānau • recommending existing national tools that may support the establishment of a national data set and/or audit system for intersex children and youth • developing a primary care referral pathway for Intersex children and youth up to 18 years of age (includes liaison with HealthPathways) • establishing NZ guidelines for newborn principles of best practice.	✓	✓	✓	✓	✓
<b>NZCYCN WEBSITE</b> A tool to profile access of the resources on the website. Est. 2014	Consult with CRGs to ensure resources are developed and loaded in a user-friendly format across multiple mediums.	✓	✓	✓	✓	✓
	Site analytics are produced and distributed to all the CN's. This provide information on access of resources, which in turn are used to inform current clinical practice.	✓	✓	✓	✓	✓
	Liaise with CRGs to ensure resources are regularly reviewed.	✓	✓	✓	✓	✓

# EXAMPLE CASE STUDIES – THREE GOOD NEWS STORIES

Following are three good news stories that reflect positive outcomes of some CN activities.

## A Radiant Young Woman; a positive eczema story

A Radiant Young Woman bounced up from her seat in the waiting room when I called her name. She had a beaming smile, a shining complexion, luxurious long black hair, dressed in t-shirt and sports shorts and wrapped completely in confidence. Had I not asked a nurse to book her an appointment to see me, I would not have recognized this young woman as the same 11 year old I met 18 months ago. That girl was downtrodden; her hands and wrists were cracked, dry and covered in green pustules. Her face was raw, her lips were tight and it hurt to move. She walked slowly and didn't make eye contact. She had only worn long sleeved shirts and track pants for years. She had never played sports. In the previous five years she had been prescribed 40 courses of oral antibiotics. She had been hospitalised twice in that time for several days for infected eczema.

What we did was not rocket science. Initially we cleaned and dressed her hands, after lancing a couple of nasty pustules. I gave her antibiotics and a week off school and got her back a week later. Then we re-taught her how to use her emollients, creams, steroids and how to identify when she need "Bleach and Emollient Baths." A week later I reviewed her and she was well, her skin was improving. Two months later, in December 2015, I phoned and asked her to come and see me, because I was worried that things may be worse. They weren't. She came in, on her own. She was well, she was wearing a t-shirt and shorts and she acknowledged that this was the first summer for years that she had done that. Her skin was still scarred, but not dry, not infected and not inflamed. In 2016 she only presented once; she was in tears, she had pustules on her hands and back; it hurt and she felt unwell. She had forgotten that she used to feel like this all the time. We treated her with antibiotics just that once in 2016.

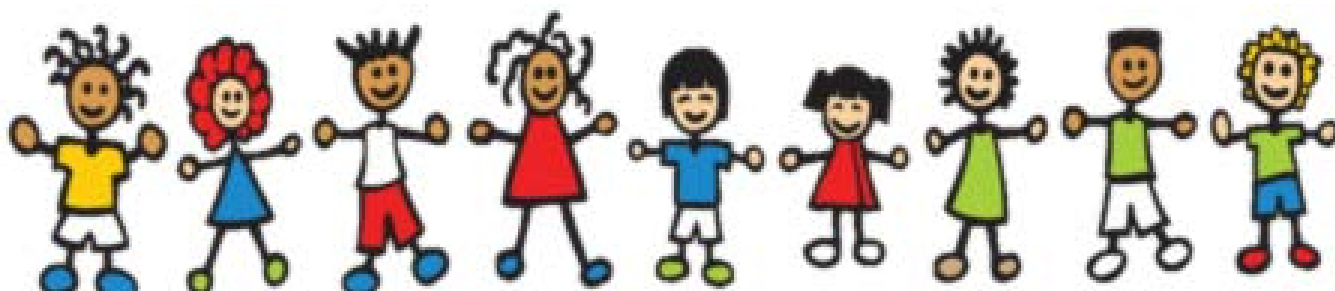
I asked this Radiant Young Woman how managing her eczema had changed her life: "I didn't use to play sports because it hurt,

now I play basketball and volleyball and I am in the school junior team. Swimming used to sting but it doesn't any more. For the last two summers I have been wearing t-shirts and shorts, but I never used to do that." I also asked her "what advice would you give the younger you?" "Keep putting on your creams all the time"

This Radiant Young Woman still uses steroids and emollient every day – she showers in emulsifier and her daily treatment in 1% hydrocortisone in emulsifier. She's heading off to her first high school camp – and she knows that she needs more of her hydrocortisone ointment for the trip. She doesn't want to come home with bad skin.

In 2015 we established an Eczema Clinic at Ora Toa Cannons Creek, Porirua. This clinic was set up to improve eczema management in a high-need community, which is predominantly Maori and Pacific, decrease our referrals to secondary care and further develop a model of cross-sector care. It is hosted by myself and Debbie Rickard; Nurse Practitioner. We usually also have GPEP1 registrars attend as part of their community outreach learning. We work like a tag-team. I lather every child in emollient, so I can model application and observe effect while Debbie revisits the history. We then share the eczema education process. What the clinic has brought to our community is a sense of confidence that we are taking their skin health seriously and that they do have a caring team to support them. We have had mothers in tears, as their children stop scratching in the room with us. Our patients are engaged. What it has brought to Debbie and myself is a sense of support and shared commitment to our goals. We both learn from each other in each clinic. We both feel like our workload is decreased because we are able to be proactive, and mostly timely, in our patient care.

With permission and thanks to Dr Annie Judkins, GP and Debbie Rickard, Nurse Practitioner, Wellington.



# Finding the needle in the haystack; a great health outcome for Baby X and family.

## A case study

**HISTORY:** Following an uneventful pregnancy, with associated good antenatal care that included normal maternal screening bloods and anatomy scans, Baby X was born at 41 weeks and the case notes record Baby X as "Good condition at birth". It was also noted that Baby X passed meconium-like stools initially, but over subsequent days the stools had become increasingly pale. At one week of age the stools were very chalky and pale although sporadically some stools did have some colour. General observations recorded as; baby alert, breastfeeding well, regular wet nappies noted. However mild scleral jaundice was also observed. Based on the above at one week of age the Lead Maternity Carer (LMC), who observed the pale stools and jaundice, referred Baby X to a Paediatrician.

**TREATMENT AND CARE.** A split bilirubin (conjugated and unconjugated bilirubin) was ordered and this identified conjugated hyperbilirubinaemia, an indicator of biliary cholestasis. Baby X was immediately referred to tertiary specialists for further investigation of possible biliary atresia. The diagnosis was confirmed as biliary atresia and Baby X had a Kasai Portoenterostomy corrective surgery aged five weeks.

**COMMENTS:** This is a positive case of finding a 'needle in the haystack'. Jaundice in babies is a common occurrence in newborn babies. In NZ around 12 babies annually (approximately 0.02% of annual deliveries) develop obstructive jaundice that requires urgent referral for immediate and ongoing treatment. The timing of corrective surgery is important for positive health outcomes for these babies. If surgery is performed earlier the need for liver transplant is potentially delayed or even avoided. The later the diagnosis is made the less successful the surgery. Transplant is not only more likely to occur but will be required often as an infant. To reduce the age of diagnosis for new babies with this condition, a quality improvement activity of the Paediatric Gastroenterology Clinical Network has been the development of (1) a referral pathway and (2) support and promote the "beware yellow" campaign. These activities seek to raise awareness of early signs of the condition for health professionals who provide care for mothers and newborn infants.

During subsequent conversations with the LMC who referred

the baby, it was identified that she had recently seen the 'beware yellow' video as part of a Midwifery education day. This update reinforced her knowledge about the importance of making an early referral when jaundice with pale stools or dark urine were observed. The prompt action of this LMC resulted in a positive outcome for Baby X and the family.

With permission and thanks to Karyn Sanson, RN MHPac; Operational Project Manager, NZCYCN Programme

## Paediatric Palliative Care (PPC) CN Education Forums

Topics from some of the PPC education forums; the provision of on-going specialist, professional development and education

- 'A beautiful story of a high-achieving and intelligent young woman in her last year at school, with a terminal illness, found a way to attend medical school without debt. Despite knowing she would not survive the year, she decided she wanted her body given to the medical school when she died and despite a difficult but well supported last stage of her life with specialist and primary services involved, her wish was achieved'.
- 'A young man who connected with his social worker sharing KFC and would talk about his dreams of chocolate cookies which led to the question what happens when you die?'
- 'Sex, drugs and Rock 'n' Roll: The dangerous world of teens with Duchene Muscular Dystrophy. How can adolescents with significant disabilities have a level of normality given a lack of space, acknowledgement and awareness of this need?'
- 'Reflections by a mother of her journey through her daughter's palliative care and what she most wants clinicians to know.'
- 'The intriguing case of Diffused Intrinsic Pontine Glioma and Cannabis' - a case presentation by a Rotorua paediatrician.





- 'Charlie Gard and Alfie Evans: Ethics, law, social media and Paediatric Palliative Care'.
- 'Spirit in Action; having time to reflect on self, impact of paediatric palliative care and by doing this, improve clinical care'.
- 'Symptom management sessions including sleep and terminal sedation, nutrition and anorexia; perinatal palliative care, grief and bereavement'.

#### WHY DID WE DO THIS?

The increasing requirement by NZ clinicians to improve palliative care for children and support for their families, and to reduce the inequitable access of specialist care in this speciality, led to the development of the monthly education forums using telemedicine and video conferencing. The topics noted above are just a few of the education sessions provided by this well-established and popular forum, facilitated and managed by members of the Paediatric Palliative CN.

The forums are on the third Tuesday morning of each month from 8 to 9am and each session has a minimum of 10 linked sites with attendees that include nurses, doctors, allied health and support workers from DHBs, Hospices and associated NGO's from around NZ.

A recent survey of the value of the forums was overwhelming. Responses noted that the sessions are valued for the professional information shared and the supporting expertise that develops from the discussions. The continuing challenge was to find a time that suited all clinicians. The forum is organised and chaired by Stephen Parkinson, a psychotherapist based at True Colours Children's Trust in the Waikato, and Karyn Bycroft, Nurse Practitioner at Starship, Auckland.

While forum speakers are often from Starship, or even the greater Auckland region, there is encouragement for health professionals from around New Zealand to present and share their experiences – a truly nationally-developed, professional education forum. Feedback from a recent survey was very positive and is summarised in the following quote:

'We have really enjoyed the content of the topics presented, the speakers have been invaluable, the case scenarios and experiential lectures leave us with memorable lessons and hold meaning and value our work – thank you and well done on again giving us the opportunity to have access to these valuable educational sessions.'

Article submitted and permission provided by Karyn Bycroft, Nurse Practitioner, Paediatric Palliative Care, Starship Children's Hospital and Stephen Parkinson, Psychotherapist, True Colours Children's Health Trust, Waikato



## COMMUNICATION AND PROMOTION

The programme has developed speciality resources that provide expert information and promote the positive benefits of being part of a nationwide 'networked' programme. Communication mediums include but are not limited to:

- The website pages that describes the programme and the increasing range of specialised resources
- The bi-annual publication of CYNet, the programme's newsletter; distribution through all the CNs which in turn is forwarded to colleagues, a wide range of DHB groups, clinical directors, Child Health Managers, regional groups, MoH links, NGOs and community groups known to the programme and/or CN members
- Updates on the PSNZ website
- CN groups on the PSNZ website
- Some CNs have their own extended groups and produce regular newsletters
- Presentations and speciality posters at conferences, nationally and internationally.

## IDENTIFIED ISSUES AND RISKS

Developing sustainable pathways and support processes for the initiation and consolidation of CNs continues to remain a challenge. The capacity of expert, specialist clinicians to manage their busy clinical workloads, and support specialist CN development, creates risks in terms how best to manage the demands of day to day responsibilities and the agreed QI activities within each CN's workplan. These processes are further impacted by:

- the limited number of specialists in NZ
- the geographic and population distribution within NZ
- the general populations' increasing expectations on what services can be provided, often following internet searches.

The challenges of finding 'time' is moderately mitigated by having 'Facilitators' to support the practical day-to-day QI activities. The limitation of time however, does impact on the capacity of clinicians to meet agreed timelines. Expectations on how and what health services can be provided can be mitigated through supportive, expert CNs.

Transition to 'business as usual' and how to manage the range of QI activities completed, or are 'works-in-progress', remains a challenge. For example, how will resources on the website be reviewed and updated? Currently all the CNs are reviewing their 'work-in-progress', and/or achievements, to seek ways in which future sustainability and transition to core business can be supported.

## THE FUTURE

The programme has formalised a structured process, designed to replicate quality improvement activities in the clinical specialities that are part of the programme. Requests to develop new national CNs outnumber the capacity to fund so the challenges of supporting new CNs along with moving others to a maintenance level will be a major focus going forward.

There is a need to further embed responsiveness to tanagta whenua as treaty partners and multicultural care in future activities, along with seeking increased consumer engagement when recommending changes and/or improvements in clinical care.

An ongoing challenge is the need to develop a flexible template to assist the transition process for children and youth to adult health services. The challenges of NZ's geographical population spread suggests that to improve equity of health services means there needs to be multiple, but credible, ways of providing clinical expertise. Therefore, the communication and promotion of the value of the QI recommendation(s) remains an ongoing challenge in the fast-moving world of information technology. The programme's capacity to proactively share resources/guidelines/best practice recommendations more



widely through web based and/or other technologies will be ongoing.

## 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 CNs. The CNs are in varying stages of development and maturity which means support needs vary.

The NZCYCN Advisory Group continues to provide governance, this includes oversight of the programme's contracted deliverables. The Secretariat provides overarching support to all CNs.

## ACKNOWLEDGEMENTS

Sincere thanks to the many clinicians and administrative personnel who continue to provide their time and expertise (over and above their daily, busy workloads) to make this programme the success it is.

Our thanks also to colleagues in the MoH for their continued belief and support for this quality improvement programme.

# Appendix 1: Advisory Group Terms of Reference

## New Zealand Child/Tamariki and Youth/Rangatahi Clinical Network Programme Advisory Group<sup>11</sup>

### Terms of Reference

#### 1. SCOPE OF THE COMMITTEE

1.1 The New Zealand Child /Tamariki and Youth /Rangatahi Clinical Network (NZCYCN) programme's Advisory Group (the Advisory Group) is a Ministry of Health (MoH) Advisory 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 Targets<sup>12</sup> will help inform the functions of the Advisory Group. Other child and youth reports and priorities identified by the sector with also inform NZCYCN functions and operations.

#### 1.3 THE FUNCTIONS OF THE ADVISORY 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 Advisory Group.

#### 2. DEFINITION

2.1 For the purpose of the Terms of Reference, the Advisory Group considers the age bands of the population group are:

- children/tamariki birth to 14 years inclusive
- youth/rangatahi 15 - 18 years

2.2 Defining strict criteria for age bands limits constructive network development. Therefore, the Advisory 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 Advisory 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 Advisory 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 Advisory 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

<sup>11</sup> Reviewed and updated by the NZCYCN Advisory Group and MoH August 2017

<sup>12</sup> <http://www.health.govt.nz/news-media/news-items/new-health-led-better-public-services-targets>

- 3.3 The Advisory Group will include a non-voting Ministry of Health representative
- 3.4 The President of the PSNZ will be an automatic member of the Advisory Group
- 3.5 The Advisory Group will co-opt specialist advice as required for specific topics

#### 4. TERMS AND CONDITIONS OF APPOINTMENT

- 4.1 All members of the Advisory Group will demonstrate recognised expertise and leadership within child /tamariki and youth /rangatahi health services.
- 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 Advisory Group may resign as a member by advising the Chairperson in writing
- 4.5 Any member may be removed from the Advisory Group at any time on the basis of discussions with the Advisory Group Chair, representative of the Ministry of Health and on advice from the PSNZ Executive.
- 4.6 The Advisory Group, in consultation with the MoH Chief Advisor – Child and Youth Health, may from time to time alter or reconstitute the Advisory Group for the purpose of decreasing or increasing the membership or filling vacancies
- 4.7 Advisory Group membership will follow an open expression of interest process with the appointment(s) made by a small Advisory Group Executive team<sup>13</sup>

#### 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 Advisory Group to be its Chair. The Chairperson will preside at every meeting of the Advisory Group at which they are present.
- 5.2 The Advisory 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 Advisory 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 Advisory Group has an obligation to conduct its affairs in an open and ethical manner. The Advisory 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 Advisory 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 Advisory Group meetings and devote sufficient time to become familiar with the affairs of the Advisory 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 Advisory Group and use of contracted funds.
- 6.5 The maintenance of confidentiality is crucial to the functioning of the Advisory 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 Advisory 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, honestly 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 Advisory Group activities as independent persons responsible to the Advisory Group as a whole. Members are not appointed as representatives of professional organisations and groups. The Advisory 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 Advisory 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 Advisory

<sup>13</sup> Composition of the Advisory Group Executive Team; Advisory Group Chair, Deputy Chair nominated from the Advisory Group, Ministry of Health representative and PSNZ CEO



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 – eight weekly. Actual and reasonable expenses for activities required by the Advisory Group of its members (e.g. travel, accommodation) will be met from the Advisory Group's budget provided prior approval is received.

9.2 The timing of meetings will be determined by the tasks the Advisory 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 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 – eight weekly.

9.4 A meeting quorum will be 50% + 1 of the Advisory Group membership.

## 10. PERFORMANCE MEASURES

10.1 The Advisory 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 Advisory 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 collection<sup>14</sup>

10.3 In carrying out its functions, the Advisory 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 Advisory 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 Advisory 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 Advisory 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 Advisory 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.

14 <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 Advisory Group<sup>15</sup>

## MEMBERSHIP LIST AT 30 JULY 2018:

Richard Aickin	From July 2014 Chair, Advisory Group; Emergency Medicine Specialist, Starship Children's Hospital, ADHB
Tim Jelleyman	President PSNZ and Paediatrician Waitemata, DHB (11/2017)
Nicola Austin	Neonatal Paediatrician, Canterbury DHB and President Elect PSNZ
Jon Buchan	RN and Portfolio Manager, Whanganui DHB (9/2014)
Julie Chambers	Senior Advisor, Child Injury Prevention
Dawn Elder	Professor and HOD, Department of Paediatrics and Child Health, Otago University, Wellington School of Medicine (2/2014)
Fiona Graham	Occupational Therapist; Senior Lecturer, Rehabilitation Teaching & Research Unit, University of Otago (11/2017)
Trish Hastie	Consumer Representative. Member of the CDHB Child Health Consumer Group (8/2017)
Toriana Hunt	Kaiwhakamahere Hauoroa Tamariki, Child Health Advisor for Maori, Canterbury DHB (8/2018)
Mal Joyce	Chair, Child Health Managers Group; Manager, Child Health Service, CCDHB (8/2013)
Rosemary Marks	Paediatrician, ADHB (Past PSNZ President and inaugural Advisory Group chair – 8/2013)
Jane O'Malley	Chief Nurse, Royal New Zealand Plunket Society (4/2018)
Mary Roberts	RN and Clinical Manager, TAHA Well Pacific Mother & Infant Service, Pacific Health, School of Population Health, The University of Auckland (3/2016)
Pat Tuohy	Chief Medical Advisor for Child and Youth Services, MoH

## IN ATTENDANCE

Mollie Wilson	CEO, Paediatric Society of New Zealand
Denise Tringham	Secretariat, Paediatric Society of New Zealand
Pam Henry	P/T Strategic Project Manager, NZCYCN Programme (May 2016)
Karyn Sanson	P/T Operational Project Manager, NZCYCN Programme (May 2016)
Laura Warwick	Advisor, Child and Family Programmes, Integrated Service Design, Service Commissioning, Ministry of Health (March 2017)

## RESIGNATIONS:

Clinical representatives for youth services; Dr Simon Denny, Dr Teri-Ann Clark, RN Shaz Iseli, have held Advisory Group appointments based on their involvement in primary care and teaching roles for youth services. Regrettably, due to work-load 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 now changed at the DHB, resigned 6/2014
Nick Baker	Paediatrician and Clinical Director, Child Health, Nelson/Marlborough DHB. Resigned August 2013 due to change in role at NMDHB
Danah Cadman	RN, 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 due to change of role at Otago University
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

<sup>15</sup> Inaugural members (2010) are those who have no date alongside their name