

# ANNUAL REPORT

1 JULY 2018 – 30 JUNE 2019

## 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
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>
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 Clinical Network program continues to grow and develop, despite the limited resources available. I remain very impressed and grateful for the willingness of individual network members to put in the time, energy and expertise to make this happen. I'm pleased to introduce two new Advisory Group members, David Barker and Cameron Grant. David is a general paediatrician at Northland DHB and has extensive experience in both urban and rural sectors in both the North and South Islands; Cameron is an Associate Professor in Paediatrics at Auckland University and a Paediatrician at Starship Children's Health.

During the past year the Advisory Group has also greatly benefited from the contributions of Toriana Hunt. Toriana is the Kaiwhakamahere Hauora Tamariki, Nga Ratonga Hauora Maori at Canterbury DHB and brought a valuable perspective to the programme's operations.

Farewell and sincere thanks to Rosie Marks who was the first Advisory Group Chair and has been a key person in the development of the NZCYCN programme over a 10 year period. Also farewell to Professor Dawn Elder for the expertise and knowledge she has brought to

the group over the past five years (although we are lucky that Dawn will be continuing to Clinical Lead of the Child Protection Network) .

The Newborn Clinical Network has had an extremely busy year that in addition to the development of resources the team has supported an external review of Neonatal Intensive Care Units in New Zealand. This Review has made a number of recommendations one of which is to implement a planned approach in the transition of neonatal care. This work will start later in 2019.

The revamped Starship web site is now operational and we are able to track the access and downloads of the resources now loaded on the site. This provides us with valuable insights into how the resources developed by our networks are being used around the country (and in some cases internationally).

Finally, I would like to put in a recommendation for the KidsHealth website (<https://www.kidshealth.org.nz>). This website contains a wealth of information for parents/caregivers on common child health problems. The information is easy to read, appropriate for the New Zealand setting, and based on credible, quality references. I find myself referring parents to this site on most of my clinical shifts in the Children's Emergency Department. Be aware that there are other KidsHealth sites (which are not of New Zealand origin) which will come up on a google search.

A handwritten signature in blue ink that reads "Richard Aickin". The signature is written in a cursive style.

Dr Richard Aickin FRACP FACEM  
Paediatric Emergency Specialist Starship Children's Hospital  
Chair, Advisory Group NZCYCN  
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# The Eighth Annual Report for the Programme

While this is the eighth annual report to MoH, this is the second report in this format.

## 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 New Zealand, national network development programme.

## WHY DEVELOP NATIONAL CLINICAL NETWORKS?

A range of international papers describe<sup>1</sup> the benefits and changes 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 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.

## 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 initiation, development and consolidation of each CN.

## STRATEGIC DOCUMENTS

A number of documents inform and support the programme's development. 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*<sup>2,3</sup>
- The Evaluation Report<sup>4</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 memberships 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 Zoom conference calls. One of the face to face meetings is a shared workshop between the Advisory Group, the CN leaders and 'facilitators.' 'Facilitators' are expert specialists who provide additional support to each CN to progress the subspecialty's agreed deliverables, key performance indicators and provide

1 Reference NHS (1999) – Scottish Executive Guidance. 12 Core Principles of MCN. 2 <http://adc.bmj.com/content/98/11/843>. 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/>

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 has established links with a 'like type' UK programme and a comparative, informal academic overview of the NZ programme was positive<sup>5</sup>. 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 NZ's child and youth health's multidisciplinary (MDT) clinicians was heard, four regional meetings attended by 175 child and youth health professionals was 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 by 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 today?

Below is a summary of developments followed by a profile of the high-level 'work in progress' and achievements, aligned to the Ministry of Health's 2016 Strategic Direction and Road for 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:**

	<p>12 subspecialty Clinical Networks (CN) established: Child Protection, Palliative Care, Diabetes, Eczema, Newborn, Gastroenterology, Cystic Fibrosis, Neurology, Sleep Medicine, Tube Feeding, Allergy and Intersex.</p>
	<p>The first CN was established late 2010 and by early 2019 12 CNs were in varying phases of consolidation with another two proposals in the early stage of approval.</p>
	<p>Annually each CN engages in one face-to-face meeting and approximately six-weekly Zoom video conference meetings</p>
	<p>Over 220 website resources/best practice recommendations/links to related websites established (all with review dates) and videos <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.</p>
	<p>The publication of the programme's newsletter CYNet (<a href="http://www.paediatrics.org.nz">www.paediatrics.org.nz</a>) profiles activities and new developments</p>
	<p>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. CN's CRGs.</p>
	<p>In 2019 in excess of 200 MDT members and consumers had, or were, contributing to the various clinical networks or supported a range of activities</p>
	<p>Contracted 'Facilitator' support is provided to each CN to assist the leader and CRG 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, NZ Child and Youth Epidemiology Service, regional health alliance groups, RNZ Plunket Inc, Telemedicine Trust (was TelePaediatrics), National Child Health Managers &amp; 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.</p>

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

The NZCYCN programme is a quality improvement tool 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:

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



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

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



**TABLE 1. NZCYCN PROGRAMME'S ACHIEVEMENTS OR WORK(S) IN PROGRESS ALIGNED TO THE 2016 MOH: HEALTH STRATEGY - ROAD MAP FOR ACTION<sup>6</sup>**

This table outlines some achievements of the CNs within the NZCYCN programme for the period ending 30 June 2019.

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>	A Child Protection Satellite Day for multidisciplinary team members of this CN is held annually and preparations are well in-hand for the event in November 2019. The day's programme includes practical information for frontline clinicians, policy updates and research findings. The meeting attracts a multidisciplinary audience, including but not limited to Nurses, Paediatricians, DHB Violence Intervention Programme Coordinators, Social Workers, and sector managers. The evaluation(s) of the day are positive.			√	√	
	Memorandum of Understanding (MoU) between DHBs, Oranga Tamariki–Ministry for Children (formerly Child Youth and Family) and Police: All DHBs have signed the MoU; the 1st schedule provides a guideline for the management of children and young people admitted to hospital with actual or suspected child abuse and or neglect; the 2nd schedule provides guidance on the DHB Oranga Tamariki Liaison role; the 3rd schedule provides guidance for the management of neglect of medical care; and the 4th schedule is a joint standard operation procedure for children and young persons in clandestine laboratories. MoU activities are ongoing between the sectors.			√	√	
	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.		√	√	√	
	Review of CP services progressed with paper accepted for publication in the J Paediatrics and Child Health <a href="https://onlinelibrary.wiley.com/doi/10.1111/jpc.14504">https://onlinelibrary.wiley.com/doi/10.1111/jpc.14504</a>					
<b>PAEDIATRIC PALLIATIVE CARE SERVICES</b> Established. 2012 <a href="http://www.starship.org.nz/palliativecarenetwork">www.starship.org.nz/palliativecarenetwork</a>	A business case for an extensive review of the End of Life Care Guidelines has been developed and presented to the NZCYCN advisory group. An RFQ has been requested and completed. Initial discussions with the clinicians required to complete this work has occurred. The CRG is currently awaiting approval from the MoH for updates to be progressed.	√	√	√	√	√
	A clinician survey regarding advance care planning to inform CRG activities has been developed and will be distributed during the first quarter on next year.	√	√	√	√	√
	The very successful monthly education forums continue with steady attendance and positive feedback. A wide variety of speakers are invited and feedback is consistently affirming on presented topics.		√	√	√	√
	The network has a MOU with Hospice New Zealand. It is reviewed and renewed every two years and the next version expected to be signed in August 2019.			√		

<sup>6</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>	The CRG are working with the Diabetes NZ – Youth section to develop a survey of families with children and young people with diabetes across New Zealand (NZ). The survey will look at resources for schools and other organisations planning overnight trips, education outside the classroom or camps. We are working with Diabetes NZ – Youth section, to complete the survey of families with children and young people with diabetes across NZ and to participate in the survey. Primary and Secondary Schools will also be asked to complete the survey, as their input will be additional, valuable information regarding resources required to support children and young people with diabetes engaged in these activities.	√		√		
	A MoU with the Aotearoa College of Diabetes Nurses is reviewed and renewed every two years with the next version expected to be signed in August 2019. Collaborative working relationships are in place to develop and share resources.	√	√	√	√	√
	The CN is encouraging all centres in NZ to collect clinical data of children and young people with diabetes (preferably in one database) that can be used for benchmarking outcomes; entering the data needs to be as time-efficient as possible, and centres may need to acquire the IT support to set the database up and carry it, and centres may need to access funding to enter the data. It will be possible to transfer data from locally held databases to the new database.		√	√	√	
	New resource providing information on glucose monitoring systems in New Zealand (including flash and continuous glucose monitoring) has been developed. It was launched at NZSSD AGM in April and is anticipated to be loaded on the networks website in September 2019.	√	√	√	√	√
	A CN member organised an excellent paediatric focussed professional development (PD) day, which was held on the special interest day, prior to the main NZSSD annual scientific meeting in Napier (7 May 2019). The PD was well received, especially the presentations by two other CN members whose research includes closed loop systems and the use of new technologies in diabetes management.			√	√	√
	Resource development includes: <ul style="list-style-type: none"> <li>National DKA protocol (nearly complete)</li> <li>Surgical guidelines (in progress)</li> <li>Camp guidelines (in early progress).</li> </ul>	√	√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<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 remain a 'work in progress' to retain relevancy and or update as required.	√	√	√	√	√
	A number of resources have been developed or updated and are available on Starship and/or KidsHealth websites including: <ul style="list-style-type: none"> <li>• Bleach Bath Information Sheet</li> <li>• Eczema Care Plan</li> <li>• Eczema Severity Score: the 'Patient-oriented Eczema Measure (POEM)' was uploaded on the 'Guidelines for the Outpatient / Primary Care Management of Childhood Eczema' page (with permission from the University of Nottingham)</li> <li>• Intro and link to Nip Allergies in the Bub (prevent allergies website)</li> <li>• The Eczema CN home page was reviewed and anticipate updates to be loaded by September including an introductory video.</li> </ul> Work in progress includes: <ul style="list-style-type: none"> <li>• Developing an article on Eczema care for publication in NZ Doctor</li> <li>• Reviewing and updating information resources for Well Child providers</li> <li>• Review of the 'Guidelines for the Outpatient / Primary Care Management of Childhood Eczema' (to ensure consistency with updated Starship In-patient and Outpatient Guidelines)</li> <li>• Eczema FAQ (mythbusters) sheet for primary care health professionals</li> <li>• Development of a video resource on eczema care for caregivers (update of the 3 steps to eczema care video series, made in 2014 and soon to be updated)</li> <li>• Incorporation of case studies outlining 'Models of Care' nationally.</li> </ul>	√	√	√	√	√
	Numerous articles and research findings have helped support and improve regular communication with the wider DHB network and feedback has always been positive about the current, clinical updates; in turn this has prompted communication from the extended membership group regarding quality improvement resources to support front line practice. Additionally, the network receives enquiries from clinicians wanting to join the mailing list that indicates information is being disseminated widely.	√	√	√	√	√
	<ul style="list-style-type: none"> <li>• Eczema Nurses Study Day held 16 November 2018.</li> <li>• Eczema workshops held for GPs at the Goodfellow Symposium, Auckland, 23- 24 March 2019. Presenter: Dr Diana Purvis.</li> </ul>	√	√	√	√	√

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>	CRG continue to progress review of existing resources although some are waiting for feedback or research to be completed by external parties. <ul style="list-style-type: none"> <li>Excellent LISA/MIST guideline and video approved to load on website.</li> <li>Endorsement process for periviability and red reflex assessment consensus statements nears completion.</li> <li>Practice recommendations for weight loss and dehydration in newborns progressing well.</li> <li>A working party developed to look at follow-up of high risk babies.</li> <li>Continue to advocate for a neonatal formulary project.</li> </ul>			√	√	√
	In partnership with the MoH, a three month project was undertaken to review Neonatal Intensive Care capacity and resourcing; project completed in March. The Report provided a number of recommendations and, with MoH, the CN Lead met with DHB Chief Executives in regard to implementing a plan to address the review's findings.		√	√	√	√
	A submission to the Health & Disability review was made.			√	√	√
<b>PAEDIATRIC GASTROENTEROLOGY SERVICES</b> Established 2013 <a href="http://www.starship.org.nz/gastroenterologynetwork">www.starship.org.nz/gastroenterologynetwork</a>	Significant work has been completed between network members, Coeliac NZ and KidsHealth to create consumer information (including a video) which will be made available via the KidsHealth website.			√	√	√
	The CRG has commenced discussion with the Allergy Network and with Australian clinicians to collaborate in resource development for the management of Eosinophilic Oesophagitis.	√	√	√	√	√
	Opportunities to engage with the health pathways group are being identified across all workstreams.	√	√	√	√	√
	Resources to raise awareness of prolonged jaundice continues to be disseminated through a variety of methods. Work regarding reflex testing of high bilirubin in babies with prolonged jaundice continues. Significant gains have been sustained in lab processes in some geographical areas however existing contracts create barriers to reflex testing being implemented in other areas.	√	√	√	√	√
	Currently there is significant variation in psychosocial services available for children with chronic conditions throughout NZ. The CRG are developing a paper to advocate for equitable service provision nationally.	√	√	√	√	√
	The assessment and referral process for babies with prolonged jaundice remains a work in progress These challenges appear to have been overcome and the CN plans to send a letter to all DHBs including the pathway highlighting the need for multi-disciplinary approach to diagnosis and ongoing care which is only available in two centres in NZ.	√	√	√	√	√

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/cysticfibrosis-network/">www.starship.org.nz/cysticfibrosis-network/</a>	Clinical Guidelines reflecting current best practice are in development with: 26 topics completed; Multiple documents and links awaiting the website upgrade prior to being loaded and pending Webmaster approval; Several more are in various stages of development. Links will continue to be created to other resources to provide supplementary information relevant to the care of children with CF in NZ by professionals and families and communities.	√	√	√	√	√
	Clinicians have engaged in Australasian working groups as part of the development of some guidelines and in benchmarking and research opportunities where possible. Physiotherapy and Nutrition guidelines have been developed using this method.  Other guidelines have required collaboration with other specialities including Gastroenterology, Surgeons, and Endocrinologists to ensure guidelines are robust.	√	√	√	√	√
	CFNZ act as the consumer representation for this network and have undertaken to ensure specific questions are put to their members in order to provide valid consumer input to inform decision making.	√	√	√	√	√
	CN has responded to discussion documents and proposed changes to MoH funded services and medications to ensure the needs of the CF community can be met.	√	√	√	√	√
	The PORT CF database provides a tool which with further development will provide clinical outcome information and assist in identification of inequalities in service provision. Work continues to improve the tool and data collection.	√	√	√	√	√
	Discussion taking place with New Zealand Formulary and New Zealand Formulary for Children regarding having a Cystic Fibrosis 'chapter' as part of their online service. This would be very useful as it would assist with updates, PHARMAC criteria and it is now the main go to for pharmacy prescribing. This looks likely to happen in 2020.	√	√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>PAEDIATRIC NEUROLOGY</b> Established 2015 <a href="http://www.starship.org.nz/neuronetwork/">www.starship.org.nz/neuronetwork/</a>	Patient/family information resources are continuing to be developed for Epilepsy and are being aligned with KidsHealth and Starship websites as appropriate. Delay in Epilepsy passport publication on Network webpage due to ongoing reviews of document due to errors identified in trial process.	√	√	√	√	√
	Paediatric Epilepsy Training (PET) continuing to be held twice yearly. >146 Paediatricians trained on PET 1, >809 trained on PET 2, >57 trained on PET. For Nurses trained- PET 1 x 19, PET 2 x 2, PET 3 x 1. For EEG Technicians x 8 trained on PET 1 and x 1 on PET 2. For Epilepsy NZ Educators x9 trained on PET 1. Extra PET 2 course to be held in July 2019 due to increased uptake. Continued uptake/interest in course by Paediatricians nationally and some international interest. Ongoing development of a sustainable strategy to support the course delivery within existing (unfunded) resources.			√	√	√
	ACC guidelines for Anti-epileptic drug usage in female patients under review as per process – final review scheduled prior to publication.	√	√	√	√	√
	Australasian Paediatric Stroke Guidelines are currently in process of being adapted for NZ context – slow process due to size of document and limited Clinician time resources being available.	√	√	√	√	√
	Identified a need for a Cognitive Behaviour Intervention for Tics Therapy (CBIT) guideline for children with Tourettes/TIC syndrome to support consistent nationwide care – initial planning stage in progress.	√	√	√	√	√
	Awaiting publication of guidelines developed in Australia for Duchennes MD Allied Health Guidelines – these will be adapted and disseminated in NZ post publication in Australia.	√	√	√	√	√
	A very successful Neuromuscular Forum for Allied Health Professionals was re-established in May 2019 with the aim to enhance and update previous training. Aim to continue forum on a yearly basis.	√	√	√	√	√
	Further guidelines on Ketogenic Diet are in process of being developed. Have published Idiopathic Intracranial Hypertension guidelines; Microcephaly guidelines; and guidelines for DMD (Duchennes Muscular Dystrophy) in regard to Allied health, Steroid use and Perioperative care.	√	√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<p><b>PAEDIATRIC SLEEP SERVICES</b></p> <p>Established 2015  <a href="http://www.starship.org.nz/sleepnetwork/">www.starship.org.nz/sleepnetwork/</a></p>	<ul style="list-style-type: none"> <li>Continue to advocate for a neonatal formulary project.</li> <li>Website reports show access to the sleep medicine network page continues at ~110-140 times per month.</li> <li>The Sleep Disordered Breathing (SDB) guidelines are available on the CN's and Australasian Sleep Association (ASA) website.</li> <li>Links to sleep-related ASA documents are loaded on the CN's website including a document on overnight oximetry for evaluating Obstructive Sleep Apnoea (OSA) and 'Clinical practice guidelines for performing sleep studies in children.</li> </ul>	√	√	√	√	√
	CRG members continue to 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.		√	√	√	√
	Transition to adult sleep medicine services – to be included in the revision of the NZ Guidelines on SDB document.		√	√	√	√
	Development of an online learning tool for oximetry for paediatricians, paediatric and ENT trainees and physiologists based on the ASA technical specifications and interpretation document (as above) with case based learning. Collaboration is ongoing between CRG and the Goodfellow Unit (University of Auckland) for development, and applications for funding.			√		
	Members are involved in the working group for revision of the Thoracic Society of Australia and NZ (TSANZ)/ ASA revision document of the 2008 Home Ventilatory Support for children. A reference document is being circulated for comment.			√		
	Progress continues with the work involved in dissemination to Primary Care. The Canterbury Community Health Pathway for OSA is 'live' (October 2018). The response and progress of this is being monitored, including liaising with ENT colleagues to assess quality of referrals.			√		
	Work is underway to maintain relevance to clinical practice of the management strategy and algorithm related to obesity in children and SDB. Ongoing involvement in the national working group on weight related comorbidities assessment and management pathway (Whanau Pakari), with revision and streamlining of specific pathway for recognition and initial investigation of sleep disordered breathing in children and youth who are obese. This will support revision and development of the NZ SDB Guidelines over the next 12 months.			√		
	Ongoing review of sleep-related KidsHealth resources and development of additional consumer resources are ongoing.			√		
	Network of centres proposed working towards development of PSM as a national service. Zoom meeting of relevant parties held in May 2019.			√		

<b>PAEDIATRIC SLEEP SERVICES</b> continued Established 2015 <a href="http://www.starship.org.nz/sleepnetwork/">www.starship.org.nz/sleepnetwork/</a>	Letter written to Minister of Health outlining findings and concerns; also copied to all Chief Executive Officers (CEOs) of District health Boards (DHBs) (and to lead paediatricians and ENT surgeons in each centre around the country).			√		
	Summary review of previous and current audit data of ENT surgery undertaken for Obstructive Sleep Apnoea (OSA) in comparison with international best practice. Action plan and appropriate targets for surgical ENT treatment for OSA for Ministry of Health (MoH).			√		
	Drive to improve the quality of increasing number of sleep studies undertaken on children in adult sleep laboratories and in private practice. Letter drafted and distributed to all NZ sleep laboratories (sent June 2019).			√		
	Involvement in the Starship ADHB Long Term Ventilation project as has national implications for resources, funding and planning of services.			√		
<b>TUBE FEEDING</b> Established 2015 <a href="http://www.starship.org.nz/tubefeedingnetwork">www.starship.org.nz/tubefeedingnetwork</a>	Guideline and resources developed with input from all disciplines; medical, nursing, dietetic, occupational therapy, speech and language therapy and psychology have been finalised and are being submitted for website approval. The evaluation of readiness for transitioning from tube to oral feed, an overview of transitioning and blenderised diet statement and flowchart are anticipated to be loaded on the website in the next couple of months. These will be followed by resources for dietitians and speech language therapists	√	√	√	√	√
	The following documents are being reviewed for submission to be published online on the NZCYCN website: <ul style="list-style-type: none"> <li>• Parental checklist for going home with a feeding tube</li> <li>• Home tube feeding discharge form</li> <li>• Frequently Asked Questions</li> <li>• General mealtime strategies</li> <li>• Transitioning from tube to oral feeding</li> <li>• Mouth play ideas for parents</li> <li>• Consumer Survey Report.</li> </ul>	√	√	√	√	√
	Report developed on a <i>national survey of DHBs to estimate the number of children on prolonged tube feeding and identify key contacts in DHBs.</i>	√	√	√	√	√
	Work is in progress to develop a quality improvement service level implementation toolkit to monitor and optimise care of long-term tube fed children.	√	√	√	√	√

CLINICAL NETWORK	WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS	PP	CH	VHP	OT	SS
<b>PAEDIATRIC ALLERGY</b> Established 2015 <a href="http://www.starship.org.nz/allergynetwork">www.starship.org.nz/allergynetwork</a>	The CN's Chair presented at the Goodfellow Symposium (workshop for GPs) in March 2019 on topic of food allergies.	√	√	√	√	
	The CN's webpage now includes: <ul style="list-style-type: none"> <li>Updated Calcium needs for children with CMA information sheet</li> <li>Recommendations for prevention of food allergy (developed by the Australian National Allergy Strategy reviewed and approved by the CN)</li> <li>Links to Anaphylaxis information in Maori, Samoan and Tongan (ASCIA information sheets).</li> </ul> A number of other resources have been completed for addition to the website: <ul style="list-style-type: none"> <li>A Guide to Food Challenges</li> <li>Competencies for the care of a patient having a food challenge – nursing and medical</li> <li>A Guide to the Ongoing care of children and young people with food allergy.</li> </ul> Other resources are under development: <ul style="list-style-type: none"> <li>Recommendations on soy infant formula</li> <li>Drug allergy guidelines</li> <li>Recommendations on immunotherapy for environmental allergies.</li> </ul> Other resources to be reviewed are: <ul style="list-style-type: none"> <li>VIT for Bee/Wasp venom allergies.</li> </ul>	√	√	√	√	
	Allergy prevention information ('preventallergies' website) provided to KidsHealth.	√	√	√	√	
<b>INTERSEX</b> Established August 2017 This is a specific two (2) year project Webpage under development	Stocktake of current definitions of intersex/DSD in use internationally in law, communities and human rights environments completed. Medical definition of intersex for NZ agreed.	√	√	√	√	√
	Newborn intersex guidelines under development.	√	√	√	√	√
	One snapshot survey and two stocktakes have been completed by the CRG that in themselves have raised awareness of the work of the group and intersex/DSD. There were a number of reports regarding interest to learn more. The stocktakes included: <ul style="list-style-type: none"> <li>Snapshot survey of health workforce knowledge about intersex/DSD children and young people.</li> <li>In March 2019 a stocktake of neonatal unit guidelines/ policies relating to neonatal ambiguous genitalia was collated.</li> </ul> In 2018 a stocktake of what education health professionals were receiving at undergraduate level in nursing schools and midwifery schools relating to people with DSD.	√	√	√	√	√

<b>CLINICAL NETWORK</b>	<b>WORK-IN-PROGRESS, PROCESSES AND/OR ACHIEVEMENTS</b>	<b>PP</b>	<b>CH</b>	<b>VHP</b>	<b>OT</b>	<b>SS</b>
<b>CEREBRAL PALSY</b>	Under development; first draft of terms of reference and Expressions of Interest advert (for CRG members) developed.	√	√	√	√	√
<b>CHILD DEVELOPMENT &amp; DISABILITY</b>	Under development; initial drafting of the Terms of Reference underway.	√	√	√	√	√
<b>NZCYCN WEBSITE</b> A metric tool to profile access and update of the resources on the web site. Est. 2014	Consult with CRGs to ensure resources are developed and loaded in a user friendly format across multiple medium.	√	√	√	√	√
	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.	√	√	√	√	√
	Ongoing liaising with CRGs to ensure resources are regularly reviewed.	√	√	√	√	√

# GOOD NEWS STORIES

A number of good news updates can be seen in each of the Network's achievements noted in previous pages and below are specific updates on positive outcomes of two Network's activities.

## Newborn CN Update

*Associate Professor Nicola Austin, Clinical Leader*

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



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

In 2018 a review of Neonatal Intensive Care Unit Capacity and Resourcing in NZ was commissioned by the Ministry of Health (MoH), supported by District Health Boards (DHBs) with the Newborn Network taking the lead. The review followed previous reviews of 2004 and 2008. The neonatal and special care unit capacity issues have been on our network workplan since we started in 2013. A three month project, undertaken by Malatest International, included extensive consultation with all neonatal services in NZ and completed March 2019. The Review's report has provided a number of recommendations. The MoH and DHB Chief Executives have agreed to support

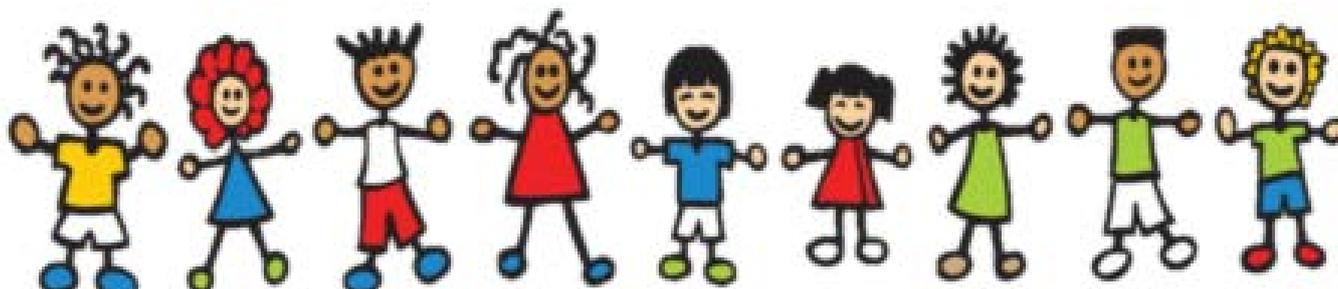
progress on three recommendations. The Transitional Care Implementation Plan project is now underway and involves key DHB clinicians and managers, MoH representatives and is chaired by this Network. This will keep more babies with their mothers on the postnatal ward and reduce some of the pressure in the NICU/SCBU. All DHBs and the MoH are engaged in the development of an Implementation Plan for Transitional Care and the timeline for completion of the fixed term project is before the end of 2019. More information on this development can be sought through DHB's services. The other recommendations are to look at the resource constraints and cot capacity as well as an improved dashboard to monitor activity and identify available cots.

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

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

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

Several of the network are also members of the Newborn Encephalopathy Taskforce that is supported by ACC. The work programme includes; (i) Developing a Newborn



observation chart and Newborn Early Warning score; (ii) Cord lactate assessment; (iii) Electronic wellbeing assessment with fetal monitoring and, (iv) Growth Assessment Protocol (GAP), the assessment of intrauterine growth.

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

An average month of website access for the Network indicates that;

Views of the Newborn clinical network	100
Consensus statement for ROP	3
Inter-hospital transfer of neonates	2
Review of the LISA-MIST video	176
Neonatal Encephalopathy	54
Neonatal Subgaleal Haemorrhage	53
Oxygen Saturation Targets	5
Treatment of hypoglycaemia with dextrose	4
Downloads	18

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

<https://www.kidshealth.org.nz/>



## Child Protection CN Update

*Professor Dawn Elder; CPCN Clinical Leader*

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

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

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

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

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

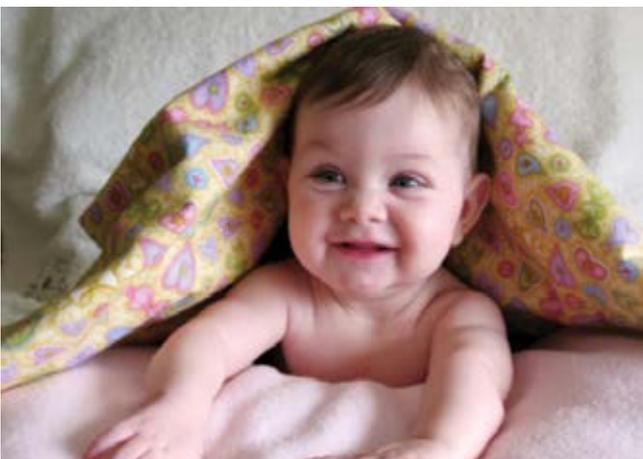
Provision of workforce development for the sector is another deliverable and the annual Child Protection satellite day remains a key action to support this. Since



2010, this annual meeting has attracted more than 100 attendees per session. The programme formulae balances national updates with practical, practice-based information and plenty of time for discussion. Preparations are well advanced for the 2019 meeting being held in Albany on Tuesday 19 November. The theme is Opening Gateways - Overcoming Barriers. For more information please follow the link [www.psnz2019.co.nz](http://www.psnz2019.co.nz)

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

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



## Identified Issues and Risks

Developing sustainability pathways for established networks continues to remain a challenge as experienced clinicians manage their clinical workloads and/or move to support other interests.

Transition to 'business as usual' and how to manage the range of quality improvement activities completed or are 'works in progress' remains a challenge. In particular how will resources on the web site be reviewed and update. 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 Programme Going Forward

- Development of two (2) new clinical networks in the 2019 – 2020 period
- Updating of resources; e.g. the successful Eczema Videos
- Building on achievements made
- Shared resources/guidelines
- National multi-disciplinary teams

## Conclusion

This report outlines the achievements, WIP and the continued support provided for the establishment, implementation and consolidation of the twelve (12) New Zealand (national) child and youth CNs.

The NZCYCN Advisory Group continues to provide governance and guidance on the agreed activities and the Secretariat provides overarching support to all CNs.

# Appendix 1: Advisory Group Terms of Reference

## New Zealand Child/Tamariki and Youth/Rangatahi Clinical Network Programme Advisory Group<sup>7</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>8</sup> will help inform the functions of the Advisory 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 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
  - Maori child/tamariki and youth/rangatahi health matters
  - The health of Pasifika Populations
  - Consumer participation and representation
- 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

<sup>7</sup> Reviewed and updated by the NZCYCN Advisory Group and MoH August 2017

<sup>8</sup> <http://www.health.govt.nz/news-media/news-items/new-health-led-better-public-services-targets>

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>9</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 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)

<sup>9</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

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>10</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.

<sup>10</sup> <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>11</sup>

## MEMBERSHIP LIST AT 30 JUNE 2019:

Richard Aickin	From July 2014 Chair, Advisory Group; Emergency Medicine Specialist, Starship Children's Hospital
Tim Jelleyman	President PSNZ and Paediatrician Waitemata, DHB (11/2017)
Nicola Austin	Neonatal Paediatrician, Canterbury DHB and President Elect PSNZ
David Barker	Paediatrician, Northland DHB (12/2018)
Barb Bradnock	DHB GM Planning and Funding representative (1/2019)
Fiona Graham	Occupational Therapist; Senior Lecturer, Rehabilitation Teaching & Research Unit, University of Otago (11/2017)
Cameron Grant	Paediatrician, Starship Children's Health, Professor in Paediatrics, University of Auckland (6/2019)
Trish Hastie	Consumer Representative. Member of the CDHB Child Health Consumer Group (8/2017)
Toriana Hunt	Kaiwhakamahere Hauroa Tamariki, Child Health Advisor for Maori, Canterbury DHB (8/2018)
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	Chief Advisor, Child and Youth Services, MoH

## IN ATTENDANCE:

Mollie Wilson	CEO, Paediatric Society of New Zealand
Denise Tringham	Secretariat, Paediatric Society of New Zealand
Josette McAllister	Senior Advisor, Child and Family Programmes, Integrated Service Design Service Commissioning, Ministry of Health
Karyn Sanson	P/T Operational Project Manager, NZCYCN Programme

## 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 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
Prof. 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 Advisory Group chair for 6 yrs, member of the Advisory 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)
Prof. 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

<sup>11</sup> Inaugural members (2010) are those who have no date alongside their name