

## **New Zealand Clinical Network for the Management of Infants, Children and Youth with Neurological Conditions Terms of Reference**

### **Purpose and Role**

To establish a national multi-disciplinary network that will provide support to New Zealand health care professionals, working across community, primary, secondary and tertiary services to deliver an equitable, high quality, cost effective and management of infants, children and youth who experience neurological conditions. The clinical network support includes infants, children, youth and their families/whanau. The aim of the Clinical Network (CN) for the management of infants, children and youth who experience neurological conditions is to facilitate clinical leadership in the development and maintenance of a nation-wide clinical service for children and youth up to 15 and when appropriate 18 years of age to basic international benchmark standards.

This will be achieved by a multi-faceted approach with the appointment of a national, multi-disciplinary Clinical Reference Group (CRG). The CRG will provide advice on service and treatment issues to the Paediatric Society of New Zealand (PSNZ) and Ministry of Health (MoH).

In particular, the CN endeavour to:

- foster a culture of a nationally coordinated approach to clinical management of paediatric and youth neurological conditions
- develop an infrastructure / work plan that supports quality improvement services, safety, equity of service provision and best value of resources
- establish a plan to support a workforce education and development programme
- develop and communicate guidelines
- identify early intervention measures and share nationally
- develop a system for the monitoring and auditing of services to inform continuous quality improvement
- develop a register to monitor the number of infants and children receiving treatment for paediatric neurological conditions
- identify and liaise with national and international bodies with relevance to infants, children and youth treatment for neurological conditions

### **CN Scope**

The scope of the CN encompasses all health care settings (community, primary, secondary and tertiary) and organisations where infants, children and youth receive treatment for neurological conditions and related services throughout New Zealand.

For the purpose of these Terms of Reference, the age bands of the population group are:

- children birth to 15 years
- youth 15 - 18 years (when appropriate)
- The CN will develop strong alliances with key organisations providing infants, children and youth with associated services in the clinical management of paediatric neurological conditions.

This includes primary health care organisations, secondary and tertiary health services and other relevant services and organisations. Defining strict criteria for age bands limits constructive network development; therefore, there will need to be some flexibility about the age at which children transition to youth services and at which youth transition to adult services. There will be an emphasis on delivering services in a developmentally appropriate manner that includes supporting the transition of young people to adult services when they achieve social independence.

### **The CRG Appointment Process**

The appointment process for the members of the CRG and the Clinical Leader will be appointed for a 12 month interim period to enable the CN to initiate implementation. The process is described below:

- the PSNZ will undertake an 'expression of interest' (EOI) process
- membership of the CRG will be decided by a selection panel appointed by the PSNZ based on information provided through the EOI process
- up to fourteen members will be selected based on level of clinical experience in treating infants, children and youth receiving treatment of paediatric neurological conditions; representation will be from professional disciplines and geographic location. The intention is for the CRG to be reflective of a multi-disciplinary approach to infants and children receiving treatment of paediatric neurological conditions and broadly represent the geographic regions of New Zealand.
- the CRG will ideally include representatives from a variety of areas which may include:
  - general practice
  - general paediatrics
  - specialist paediatrics
  - nursing
  - Maori and Pacific health providers
  - pharmacy
  - community interest/support groups
  - consumers
  - as required additional specialists can be invited for discrete pieces of work
- the Interim Chair of the CN will be appointed by the Chair of the Advisory Group for a 12-month period
- following the 12-month period, further EOIs will be sought for all the membership positions. Current members will be eligible to continue

### **Communication and Meetings**

The CRG's communication process and meeting schedule is as follows:

- the majority of contact within the group will be via e-mail
- there is an expectation that members will review requests in a timely manner, i.e., urgent e-mail correspondence will be responded to within two working days and non-urgent will be responded to within five working days
- meetings will be held up to 4 times per year by tele/video conference and a minimum of 1 face-to-face meeting
- these meetings will be supported by the CN's National Secretariat
- a quorum for a formal meeting will require 50% of members + 1 (excluding the National Secretariat attendee)
- information on the network's development and resources will be loaded on the national CN website once the approval process has been complete  
<https://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/>

## Accountability and Reporting

The CRG is accountable to the PSNZ

- Reporting will be by the Chair and will detail specific deliverables that (aligned to the CN's work plan) that will need to be reported on
- Reports will be forwarded to the Secretariat in a timely manner and per agreed schedule
- Minutes of meetings to be recorded and distributed to the CRG no later than two weeks post meeting

## CN Roles and Responsibilities

The **CRG members** will be responsible for:

- actively participating and contributing to meetings, processes and tasks of the CN
- supporting the Chair
- providing advice from their areas of expertise to other CN members
- responding in a timely manner to requests for information and advice from other CN members
- reporting back to their own organisations and related organisations
- not disclosing any confidential information or making media statements on matters relating to the CN without the prior approval of the whole CRG and Chair

The role of the **Chair** is to:

- provide leadership and support to all clinicians in the secondary and tertiary sectors plus links with professional bodies and other specialist medical staff
- provide leadership and support to all clinicians and associate staff within DHBs for the development of national standards, referral guidelines and information systems
- establish sustainable links with appropriate primary care organisations, non-government organisations (NGOs) and relevant, specialty clinical and consumer groups
- support the provision of treatment with appropriate escalation and de-escalation of care
- work closely with the PSNZ / CN's National Secretariat to develop a sustainable, cost effective national network

The **National Secretariat** will provide support to the CN including:

- providing administrative support to CN meetings through distribution of the agenda and recording and distribution of the minutes
- oversight of business rules and financial matters
- coordination and support for the development of the annual work plan
- coordination and support for agreed communication/information processes
- project management of specific projects as per agreed CN annual work plan

The **CN** will be defined by:

- service delivery occurring close to where children and young people live where possible
- workforce distributed across all DHB regions. This may be as a hub and spoke model.
- providing a value component to infants and children receiving care for neurological conditions through:
  - improved integration of care across the continuum of treatment
  - linking paediatric neurological services into a multi-disciplinary network committed to identifying and adopting quality practice
  - striving to achieve consistency through agreed standards, promotion of clinical leadership, developing training, sharing information, key performance and outcome indicators
  - the promotion of audit and evaluation of service change to inform quality improvement practices

The **CRG's** tasks for the contracted period are to:

- collaborate with other relevant organisations (including DHBs, MoH and the PSNZ)
- finalise and sign off the terms of reference for the CN before 30 March 2016
- agreed an annual work plan with defined and time bound deliverables
- continue to develop and implement activities that will address variations in paediatric neurological services, resources and skills and strengthen parent education
- explore options that support the development of a minimal set of national data/information to inform practice change and support positive health gains and/or outcomes
- identify and liaise with national and international bodies with relevance to paediatric neurological services
- establish a communication plan that informs all New Zealand health care professionals working across community, primary, secondary and tertiary services and other interested parties of the development and work of the network
- plan for sustainability of the network post 30 June 2017 including governance and operational functions

### **Review**

These Terms of Reference will be reviewed by the CRG before 31 March 2017 at which time a decision will be made on the structure of the CN.