

Cerebral Palsy Clinical Network Terms of Reference

Purpose and Role

To establish a national multi-disciplinary network that will support clinicians working across community, primary, secondary and tertiary services to deliver high quality, cost effective and integrated Cerebral Palsy programmes of care for children, youth and their whanau. This is a quality improvement programme with the aim of providing clinical leadership in the development and maintenance of a nation-wide clinical service for children/tamariki, youth/rangatahi and their families/whanau who seek services and support for Cerebral Palsy care.

The Cerebral Palsy Clinical Network will aim to identify and minimise inequities that exist for children/tamariki, youth/rangatahi and their families/whanau with lived experience of cerebral palsy throughout all of Aoteroa, New Zealand. Inequities also exist for professionals working towards delivering effective interventions. Inequities may include cultural, ethnic, service delivery, multidisciplinary support, regional resourcing and opportunities, financial barriers and costs, and opportunities for knowledge translation and sharing.

The aim of the Cerebral Palsy Clinical Network (CN) will be supported through a multi-prong approach with the appointment of a national, multi-disciplinary Clinical Reference Group (CRG) that is strengthened by the appointment of clinical leaders from medical, nursing, allied health professionals, bicultural advisor(s) and consumer(s) representatives. The CRG will provide advice on service(s), related care matters and treatment issues to the New Zealand Child and Youth Clinical Network's (NZCYCN) Governance Group and the Ministry of Health (MoH).

In consultation with the NZCYCN Governance Group, and in collaboration with the NZCYCN Programme's Child Development and Disability Clinical Network (CD&D CN), agreed a process to become a more integrated and/or aligned CN with the CD&D CN, within the overarching NZCYCN programme.

In particular, the Cerebral Palsy CN will:

- Develop and promote best practice recommendations and resources for health professionals that support early diagnosis, early intervention, and effective early management and care of Cerebral Palsy
- Provide children/ tamariki and young people / rangatahi with Cerebral Palsy voices to the CN's planning and implementation
- Design and develop improved transition of young people/rangatahi and their families/whanau with Cerebral Palsy from paediatrics into adult health services
- Support the development of a sustainable pathway for the NZ Cerebral Palsy Register so that data from the Register can support and inform the CN's work streams
- Create comprehensive understanding of key aspects of specific treatments, for example, but not necessarily limited to, Selective Dorsal Rhizotomy and intensive therapies amongst District Health Boards (DHBs) and related Ministries (e.g. Ministries of Health, Education and Social Services)
- Promote active participation in all aspects of life for children/tamariki and youth/rangatahi with Cerebral Palsy
- Continue to develop a workforce education and development programme

- Develop recommendations for monitoring and supporting services to promote continuous quality improvement of Cerebral Palsy care
- Identify and liaise with national and international bodies with relevance to childhood Cerebral Palsy

CN Scope

The CN's scope encompasses all health care settings (i.e. community, primary, secondary and tertiary) and organisations where Cerebral Palsy care and related services are provided for children/tamariki, youth/rangatahi and their families /whanau throughout New Zealand.

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

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

The Cerebral Palsy CN will develop strong alliances with key services providing child and youth Cerebral Palsy programmes including child development and disability services, paediatric and Cerebral Palsy services, primary care organisations and other relevant services and organisations. Defining strict criteria for age bands may limit constructive network development; therefore, there will need to be some flexibility about the age at which children transition to youth services and at which age 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 Group Appointment Process

The appointment process for the CRG members and the Clinical Leader(s)/Chair¹ will be as follows:

- the NZCYCN Secretariat will undertake an 'Expression of Interest' (EOI) process
- CRG membership will be agreed by a selection panel appointed by the NZCYCN Secretariat and will be based on information provided through the EOI process
- The membership of the Cerebral Palsy CRG will be between 10 and 18 members who will be selected based on level of experience in child and youth Cerebral Palsy care; and will be reflective of multidisciplinary representation and geographic location. The intention is for the CRG to have a multi-disciplinary approach to Cerebral Palsy care and be broadly representative of New Zealand regions.
- the CRG will ideally include representatives from a variety of areas which may include, but is not limited to:
 - consumers and their families/whanāu
 - engagement with the Cerebral Palsy Society of New Zealand (Inc)
 - general practice
 - general paediatrics
 - sub-speciality paediatricians who work with individuals with Cerebral Palsy e.g. neurology, rehabilitation
 - nursing
 - a range of allied health professionals
 - Well child / tamariki ora providers
 - Maori and Pacific health providers
 - community interest/support groups
 - as required additional specialists can be invited for discrete pieces of work
- the CRG Chair will be nominated by the CRG or if agreed, the CRG may initially appointed a Chair on an interim basis for up to 12 months to oversee the CN's initial development

¹ Note: The term Clinical Leader and Chair are interchangeable and used per the leader's preference.

Communication, Meetings and Website Resources

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

- the majority of contact within the CRG 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 three working days and non-urgent will be responded to within five working days
- meetings will be held up to six times per year by video/teleconference (Zoom) and a face-to-face meeting. These meetings will be supported by the NZCYCN's Secretariat
- agendas will be circulated at least five days prior to meetings. Minutes will be circulated no later than a fortnight following the meeting date
- A quorum for a formal meeting will require 50% of members + 1
- The CN will contribute articles to the NZCYCN programme's publication *CYNet* and MoH reports. This to include an initial introduction article for *CYNet*
- the CN will provide resources and information on the NZCYCN programme's website on the [Starship Children's Hospital's website platform](#) (and follow the agreed process for the submission of this material)
- The CN will provide support for the updating of parent information on the [KidsHealth website](#).

Accountability and Reporting

The CRG is accountable to the NZCYCN Programme's Governance Group

- Quarterly reporting will be by approved by the CN's Chair
- Quarterly reports will be forwarded to the NZCYCN Programme's Secretariat in a timely manner
- Quarterly CN reports will form part of the NZCYCN Programme's reports to the MoH
- Minutes of meetings will be recorded and distributed to the CRG

The Network Roles and Responsibilities

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

- actively participating and contributing to meetings, processes and tasks of the CN; to include agreeing the annual work plan and the initiation of a strategic plan
- supporting the Clinical Lead(s) and, when appointed, the Facilitator
- providing advice from their areas of expertise to other CN members
- providing timely responding to requests for information and advice from other CN members
- reporting back regularly to their own and related organisations
- not disclosing any confidential information or making media statements on matters relating to the CN without the prior approval of the full CRG, the Chair and in matters of national significance, the Chair of the NZCYCN Programme's Governance Group

The role of the **Clinical Leader/ Chair** is to:

- work in collaboration to provide complementary leadership and support to specialist clinicians, consumers and CRG membership
- provide leadership and support to relevant clinicians and associate staff within DHBs for the development of national standards, protocols, referral guidelines, practice guidelines and/or information systems. This includes working with primary, secondary and tertiary health care providers
- establish sustainable links with appropriate primary care organisations, relevant specialty clinical groups, bicultural advisors and consumer group(s)
- liaise with and develop integrated programme(s) with regional alliances, DHBs, the primary care sector and consumer groups
- support the provision of treatment with appropriate escalation and de-escalation of care
- work closely with the NZCYCN Programme's Secretariat to develop a sustainable, cost effective national network

The **NZCYCN Programme's Secretariat** will provide support to the CN including:

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

The **CN** will be defined by:

- supporting service delivery occurring close to where children / tamariki and young /rangatahi people live where possible
- ensuring the work and strategic plans have a quality improvement focus that includes timebound aim(s) and deliverables aligned with the CN's strategic high-level deliverables.
- as able and relevant, the provision of professional support for the multidisciplinary (MDT) workforce distributed across all DHB regions
- the provision of added value through:
 - formal MDT networks that link services committed to identifying and adopting quality improvement initiatives and innovative practice(s)
 - striving to achieve consistency through agreed standards / practice recommendations
 - the promotion and support of clinical leadership
 - support for shared professional development opportunities
 - the sharing information across the MDT sector
 - the agreement of key performance indicators that support quality improvement activities and as relevant and able promote audit and evaluation

The **CRG's** initial tasks (first year) are to:

- finalise and sign off the CN's Terms of Reference (ToR)
- develop a minimal set of high-level deliverables
- create an annual work plan and initiate the development of a strategic plan
- in collaboration with the Child Development and Disability CN agreed a transition plan to become a structured workstream under the umbrella of the Child Development and Disability CN
- collaborate and initiate formal agreements with 'like type' and other relevant organisations
- initiate development of a model of care for Cerebral Palsy services
- as able and relevant, audit current service provision, in particular, gaps in service provision for key target age-groups
- initiate a proposal for a workforce education and development programme
- identify and liaise with national and international bodies with relevance to childhood Cerebral Palsy

The **CRG** workplan following year one is to:

- review, and as relevant, amend the ToR
 - agree the Clinical Leader / Work Stream Chair role going forward
- agree the CN's annual work plan and ensure this is aligned to the CN's strategic plan
- In consultation with the NZCYCN Governance Group agreed a process to become a more integrated and or aligned CN with the Child Development and Disability CN within the context of the overarching NZCYCN programme.
 - reflect on the development of the strategic plan including the term of the Cerebral Palsy CN and requirements for sustainability in succeeding years.

Review

These Terms of Reference will be reviewed by the CRG prior to 30th June 2022