

New Zealand Child & Youth Cystic Fibrosis Clinical Network Terms of Reference

Purpose and Role

To establish a national multi-disciplinary and multi-agency network that will support clinicians and non-government organisations working across community, primary, secondary and tertiary services to deliver high quality, cost effective and integrated treatment for children and youth with cystic fibrosis (CYwCF) and their family/ whanau.

The aim of the Clinical Network (CN) for CYwCF is to provide clinical leadership and collegial support in the development and maintenance of a nation-wide, clinical service for children and young people. This will be achieved with the appointment of a Clinical Leader and a nationally sourced, multi-disciplinary/ multi-agency Clinical Reference Group (CRG).

In particular, the CN will:

- foster a culture of a nationally coordinated care for child and young people with cystic fibrosis which promotes equity of access to services across the continuum of care. This culture will be informed by the Standards of Care document
- develop a system for the monitoring and auditing of services to inform continuous quality improvement
- identify and liaise with national and international bodies with relevance to children and young people with cystic fibrosis
- develop a model of care
- establish a workforce education and development programme

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
- value added by linking services into a multidisciplinary network committed to identifying and adopting quality practice, striving to achieve consistency through agreed standards, promotion of clinical leadership, developing training, sharing information, indicator development, promoting audit and evaluation

The Clinical Leader and CRG Roles and Responsibilities

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

- work in collaboration to provide complementary leadership and support to all clinicians
- ensure that the activity of the CN is in keeping with the Terms of Reference (ToR)
- provide leadership and support to all clinicians and associate staff within District Health Boards (DHB) for the development of national standards, referral guidelines and information systems. This includes working with primary care, secondary and tertiary health care providers
- establish sustainable links with appropriate primary care organisations, relevant specialty clinical groups and consumer groups
- liaise with and develop integrated programme(s) with DHB, the primary care sector and consumer groups
- support the provision of treatment with appropriate escalation and de-escalation of care
- work closely with the NZ Child and Youth Clinical Network Advisory Group (NZCYCN) and the Secretariat to develop a sustainable, cost effective national network
- The Chair, or nominated CRG member, will represent the interests and aims of the CN in any external meetings and committees to which the CN is invited to attend

- The Chair can be from any professional discipline represented in the CN. The position of Chair will be for a fixed term of two years, with a maximum of four years
- The Chair will partner the Paediatric Society of New Zealand (PSNZ) CEO to ensure good governance of CN processes and expenditure

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

- actively participating and contributing to meetings, processes and tasks of the CN
- supporting the Clinical Lead and contracted facilitator
- providing advice from their areas of expertise to other CN members
- responding in a timely manner to requests for information and advice from other CRG members and the Secretariat
- 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
- providing nominations for representation on external committees where relevant to the care of CYwCF and includes representation from CFNZ
- collaborate with other relevant organisations (including the Ministry of Health (MoH) and the PSNZ)
- developing processes to audit current service provision and or gaps in service provision
- identify and liaise with national and international bodies with relevance to children and young people with cystic fibrosis
- the development of a model of care for CYwCF

Membership

The initial appointment process for the members of the CRG and the Clinical Leader(s) was through an 'expression of interest' (EOI) process and resignations and/or additional members will continue to be appointed using an EOI process

- between 8 – 12 members will be appointed based on level of clinical experience in CYwCF, professional disciplines represented and geographic location. The intention is for the CRG to be reflective of a multi-disciplinary approach in the treatment and care of CYwCF and to broadly represent the geographic regions of New Zealand (NZ)
- the CRG will ideally include representatives from a variety of areas which may include:
 - general practice
 - general paediatrics
 - nursing
 - Maori and Pacific health providers
 - dietetics
 - pharmacy
 - community interest/support groups
 - consumers
 - social workers
 - physiotherapists
- the CRG Chair will be nominated by the CRG
- Membership of the CRG will be for no longer than six years
- the CRG will ensure the CN functions in accordance with its purpose and role

The **National Secretariat** will provide support to the CN through

- the provision of administrative support including the management of meetings through distribution of the agenda, recording of the minutes and, when required arranging travel
- oversight of business rules and financial matters
- coordination and support for the development of the annual work plan and strategic plan
- coordination and support for agreed communication/information processes
- project management of specific projects as per agreed CN annual work plan

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 two working days and non-urgent will be responded to within five working days
- any material submitted for CRG approval requires a quorum provided verbally or via email within the specified timeframe
- meetings will be held up to four times per year by teleconference or videoconference with up to two of these meetings being held face-to-face. These meetings will be supported by the Secretariat. The agenda 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's publication CYNet as relevant
- The CN will provide resources and information on the NZCYCN web site (<https://www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-clinical-networks/>) 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 (<https://www.kidshealth.org.nz/>)

Accountability and Reporting

The CRG is accountable to the NZCYCN Advisory Group. Reporting will be by the Chair as defined in the Clinical Leader or the contracted support person's contract

- Regular reports will be forwarded to the Secretariat in a timely manner and per agreed schedule
- The work plan will be reviewed at all meetings and achievements noted and signed off as appropriate. An annual review of the Workplan will be completed and noted
- Minutes of meetings to be recorded and sent as part of the above reporting requirements
- The PSNZ CEO together with the Chair will be responsible for coordinating advice and support for the CRG
- The CN is a collaborative venture between the PSNZ, non-government organisations (including the Cystic Fibrosis New Zealand (CFNZ), medical nursing, allied health and other health professionals across New Zealand who provide care for CYwCF
- The CN is funded by a MoH fixed term contract with PSNZ. The contract supports activities that promote the development of a managed clinical network amongst paediatric health professionals in NZ.
- The term of the CN will be underpinned by the MoH's contract with PSNZ
- During the period of operation, the CN will endeavour to work towards a sustainable operating model

Review

The Terms of Reference will be reviewed by the CRG every three years with any changes agreed by a quorum of the CRG and revised Terms of Reference distributed.