

# Terms of reference

## Technical Advisory Group

### Complex Epilepsy National Service Improvement Project

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#### Background

In 2010 a programme of National Services and National Service Improvement Programmes was endorsed by the Minister of Health, where it was identified that a national, coordinated, approach was required.

Services were considered for National Service status to improve access, consistency, level of investment, and clinical and financial viability. Two different approaches are in place to achieve this:

*National Services* – services that should be nationally planned and/or funded centrally by the Ministry of Health (the Ministry)

*National Service Improvement Programmes* – services that require action from the centre to lift District Health Board (DHB) performance, but are not requiring the additional step of Ministry purchasing – the focus is on centrally coordinated performance improvement activities

Complex Epilepsy was identified as a service that would benefit from a national service improvement approach to deliver accessible and consistent services for people with Epilepsy, improved patient experience and better utilisation of existing resources.

Complex Epilepsy has not been formally defined but is considered to be an alternative descriptor for Drug-resistant Epilepsy, defined by the International League Against Epilepsy (ILAE) Commission as “a failure of adequate trials of two tolerated and appropriately chosen and used anti-epilepsy drug schedules (whether as mono therapies or in combination) to achieve sustained seizure freedom”

A formal service review was undertaken in 2012 which identified a number of challenges in current provision of services, including the lack of useful epidemiological data, treatment guidelines, patient pathway or referral guidelines and performance measures, and the corresponding absence of a comprehensive care model. This makes it difficult to firstly establish the level of need for surgical intervention and to identify if or how better primary and secondary care could reduce the progression of patients to need complex care.

## Purpose

This Technical Advisory Group (TAG) has been established to provide the specific knowledge and expertise to inform and guide the information and processes necessary to complete a national service improvement project.

## Functions and Roles

The main objectives of the project are to:

1. Improve understanding of the level of need for and current provision of care for patients with complex epilepsy
2. Develop New Zealand appropriate guidelines and pathways for the effective management of patients with epilepsy:
  - a. across the continuum of care, including an outpatient model of care
  - b. focused on early diagnosis and appropriate referral for specialist care
  - c. supporting chronic condition management in the community.
3. Identify and recommend the optimal provision of specialist interventions such as neurosurgery, pharmaceutical trials and diets for that group of patients for whom these interventions provide the only hope of managing their condition.

## Membership

The TAG should include the following members/disciplines to ensure consideration of all aspects of a complex epilepsy model of care

- DHB Clinician/s (Adult focus)
- DHB Clinician/s (Paediatric focus)
- DHB Clinician – Nutrition
- Nurse specialist
- Referring DHB Neurologist
- Referring DHB Paediatrician
- DHB Planning and Funding Manager
- DHB Service Manager
- Consumer/Family representative
- Epilepsy New Zealand representative
- Primary care practitioner
- Ministry of Health

Additional expertise may be co-opted at any time as needed.

Other interested parties and consumer groups will not be part of the Advisory Group but will be invited to provide feedback on drafts for discussion by the working party before the drafts are circulated for DHB endorsement.

## Chairperson

All meetings must be presided over by a chairperson. In the event of the chairperson being absent, an alternative will be elected as acting chairperson by those members present. The chair will be confirmed/nominated at the first meeting.

## Quorum

Half the group

## Conflicts of interest

Conflicts of interest will be declared at the commencement of the meeting, and will be managed by the Chair.

## Decision making

Decisions and recommendations will be consensus agreement of the group. Where a conflict of interest is identified, the relevant parties will abstain from decision making. The Chair will manage situations where consensus cannot be reached.

## Accountability

Each member is accountable to his/her organisation. They shall inform their organisation of the TAG activities, and communicate both agenda and minutes.

The TAG is accountable to the Ministry of Health for the delivery of the agreed functions and roles.

## Working arrangements

It is expected the project will be of 12–18 months duration, and that there will be 2–3 face to face meetings, and teleconferences as required to progress the agreed work plan.

The Ministry of Health will provide a secretariat function for the TAG. Minutes will be issued within a week of the meeting, and finalised at the next meeting.

DHBs and other health organisations are expected to support the attendance of their staff at the meetings and make travel arrangements. Consumer and primary care representatives' attendance fees and travel costs will be met in accordance with Ministry of Health policy.