

Reducing Neonatal Encephalopathy in New Zealand

The Neonatal Encephalopathy* (NE) working group

Why was the NE working group established?

The Perinatal and Maternal Mortality Review Committee (PMMRC)'s purpose is to review New Zealand's perinatal and maternal deaths, and report to the Health Quality and Safety Commission (HQSC) on how to reduce the numbers of preventable deaths. The PMMRC's role also includes developing strategic plans and methodologies to reduce perinatal morbidity. Neonatal encephalopathy (NE) was identified as an area where there may be the potential for improvement of services and outcomes for babies. In late 2007 the Neonatal Encephalopathy Working Group was established by the PMMRC and was charged with reviewing New Zealand data on NE.

Why NE?

Despite advances in obstetric and neonatal care, NE remains a major cause of brain injury in the term newborn infant. Of those infants affected by NE, 10-60% will die and at least 25% of those surviving will have long term neurological complications resulting in chronic handicapping conditions such as cerebral palsy, neuro-developmental delay, blindness, hearing deficits and epilepsy. Although there are a number of population studies looking at the prevalence of NE internationally it is important to collect and report on local New Zealand data.

What is the NE working group doing?

To establish the true size of the problem of NE in New Zealand, the first priority of the group is to collect data on the prevalence in New Zealand in order to form a national data set. It is hoped that predictors and/or mediators of NE will also be identified, potentially allowing the development and implementation of effective preventative and remedial therapies with a view to reducing both the occurrence and severity of NE in New Zealand.

How does the NE working group collect data?

An ongoing observational audit commenced in 2010. NE was included as one of the conditions on the New Zealand Paediatric Surveillance Unit (NZPSU) monthly reporting card from January 2010 - 2012. From 2013 identification of NE cases has been by key clinicians in neonatal and special care baby units

- Completion of the *PMMRC Baby Rapid Reporting Form for an Infant with Moderate to Severe Neonatal Encephalopathy* by the attending paediatrician
- Completion of the *PMMRC Mother Rapid Reporting Form for a Baby Diagnosed with Neonatal Encephalopathy* by the Lead Maternity Carer.
- Collection of patient records (mother and baby – from DHBs and LMCs) for national case review

From 2016 babies born from 35-37 weeks gestation will also be included in this audit. The purpose of this is to document the increased use of hypothermia in infants <37 weeks gestation who have a clear hypoxic ischaemic insult.

What will this mean for me as a paediatrician?

If you have cared for a baby identified as having Moderate and Severe NE please complete the *PMMRC Baby Rapid Reporting Form for an Infant with Moderate to Severe Neonatal Encephalopathy* online. The website can be accessed at: www.otago.ac.nz/pmmrc. This form shouldn't take more than 20 minutes to complete.

Definition and Staging on Neonatal Encephalopathy*

A clinically defined syndrome of disturbed neurological function within the first week of life, manifested by difficulty in initiating and maintaining respiration, depression of tone and reflexes, subnormal level of consciousness and often seizures. From 2016 any baby from 35 weeks gestation will be included in the dataset

NE Staging	Stage 2 / Moderate	Stage 3 / Severe
Level of consciousness	lethargic or obtunded	stuporous
Muscle Tone	mild / moderate hypotonia	flaccid
Posture	strong distal flexion	intermittent decerebration
Stretch reflexes	overactive	decrease or absent
Suck	weak or absent	absent
Moro	weak / incomplete high threshold	absent
Autonomic Function	generalized parasympathetic overactivity	both systems depressed
Seizures	common	uncommon

What will this mean for me as a Lead Maternity Carer (LMC)?

As the LMC of a baby that has been identified as having NE, you will receive details to assist you to complete the PMMRC Mother Rapid Reporting Form for a Baby Diagnosed with NE online. The website can be accessed at www.otago.ac.nz/pmmrc. A paper version of the form is available if you prefer to complete and return this. This form is similar to the current PMMRC rapid reporting form and shouldn't take more than 20 minutes to complete. You may also receive a request for a copy of your LMC notes.

Will individuals be identified in the process?

No. As with the PMMRC process a full data set is collected but this is de-identified in the report and aggregate data presented so no individual infant or mother will be identified. The investigators, as agents of the PMMRC, are under strict confidentiality obligations under Schedule 5 of the New Zealand Public Health and Disability Act. The penalty for disclosing personal information is a fine of up to \$10,000, and individuals are liable to professional disciplinary proceedings.

The PMMRC and members of the NE Working Group are the only people who will have access to raw data and/or clinical records during or after the study. Upon completion of the project, the raw data will be transferred to secure storage unit, and will be the responsibility of the PMMRC.

How will information from the audit be used?

Data gathered in this audit is used to identify the number of newborn infants with moderate to severe NE in New Zealand, the distribution of these affected infants in terms of geographic location and the spread between level 2 and level 3 neonatal units. It will determine possible predictors of the condition and how these infants are managed. It is intended that this audit will identify areas for development and implementation of effective preventative and remedial therapies with a view to reducing both the occurrence and severity of NE.

Who is on the NE working group?

The members of the NE working group are clinicians involved in the provision of perinatal care and representatives from associated areas. The current members are:

- Dr Jutta van den Boom (Chair), neonatal paediatrician, Waitemata DHB
- Dr Kitty Bach, neonatal paediatrician, Auckland DHB
- Dr David Bailey, obstetrician and gynaecologist, Northland DHB
- Dr Malcolm Battin, neonatal paediatrician, Auckland DHB
- Ms Karen Bennington, neonatal nurse practitioner, Capital & Coast DHB
- Ms Robin Cronin, midwife, Auckland
- Ms Anne Jackson, neonatal nurse practitioner, Canterbury DHB
- Ms Suzanne Miller, midwife, Wellington
- Mr John Tait, Chair PMMRC
- Dr Kristy Wolff, obstetrician and gynaecologist, Northland DHB

Supported by Vicki Masson – PMMRC National Coordinator

Further information on the Perinatal and Maternal Mortality Review Committee and the Neonatal Encephalopathy Working group can be found on our website <http://www.hqsc.govt.nz/our-programmes/mrc/pmmrc/>