

Neonatal Encephalopathy Working Group of the Perinatal and Maternal Mortality Review Committee (12 December 2016)

Terms of Reference

Background

1. The Neonatal Encephalopathy Working Group (“the Working Group”) is a Working Group of the Perinatal and Maternal Mortality Review Committee (PMMRC). The PMMRC is appointed under section 59e of the New Zealand Public Health and Disability Act 2000 (“the Act”) by the Health Quality and Safety Commission (the Commission).
2. The Working Group was established by the PMMRC in late 2007 to review data with the aim of improving outcomes and services for babies with neonatal encephalopathy (NE).
3. For the purposes of the NE Working Group, NE can be defined as:

“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” (Nelson & Leviton, 1991).

Function

4. The wider functions of Mortality Review Committees are set out in section 59e (1) (a) and (b) of the Act. The Working Group will report to PMMRC as “agents” of the PMMRC and the legislative responsibilities that apply to PMMRC will apply to the Working Group and any people involved in the reviews.
5. The Working Group is required to review and report to the PMMRC on NE mortality and morbidity in New Zealand and identify quality improvement initiatives with the aim of reducing the prevalence and severity of NE and improving quality of services and outcomes for babies.
6. Applicable provisions

6.1. The provisions of Schedule 5 to the Act that apply in relation to a Mortality Review Committee, (s59E of the Act) also apply to the Working Group.

Scope

7. The Working Group is required to review and report to the PMMRC on NE mortality and morbidity and identify quality improvement initiatives aimed at reducing NE and improving neonatal outcomes within the Working Group’s scope.

Expected Activities

8. The Working Group will:

- 8.1. Ensure the security of personal information referred to in clause 3 of Schedule 5 of the Act.
- 8.2. Analyse and use data collected through NE data collection forms and case reviews to develop recommendations. The effectiveness of the recommendations will be monitored via ongoing review.
- 8.3. Advise the Commission (through PMMRC) on strategies focusing on inequity to reduce cases of NE and improve outcomes of babies affected by NE.
- 8.4. Maintain effective linkages and alignment (through the PMMRC) with the Ministry of Health, National Maternity Monitoring Group and DHB maternity quality and safety programmes.

In carrying out its functions the Working Group must ensure:

- 8.5. Appropriate consultation when developing methodologies to carry out its functions and disseminating its findings.
- 8.6. Any advice and recommendations comply with the laws of New Zealand and have evidence of benefit/effectiveness.
- 8.7. The findings of the Working Group are reported at least annually.

Composition

9. The Working Group will have a maximum of 9 members appointed by the PMMRC.
10. Members should have combined knowledge and expertise in the following areas: paediatrics, obstetrics and gynaecology, clinical epidemiology, midwifery, neonatal nursing, neonatology, health quality and risk management, consumer engagement and cultural understanding of Māori and Pacific health.
11. Applications will be invited from appropriate representative bodies.
12. Members will have the ability to work strategically and will have knowledge of relevant communities.
13. Members will collectively hold knowledge of and have national credibility in New Zealand's maternity system.
14. The Chair of the PMMRC may attend meetings.

Terms and Conditions of Appointment

15. Members of the Working Group are appointed by the Commission for a term of office of up to three years. The terms of office of members of the Working Group will be staggered to ensure continuity of membership. Members may be reappointed from time to time, and there is no guarantee of reappointment.
16. Working Group members who are also PMMRC members will retain their PMMRC terms and conditions, which are established by the Commission.

17. Members will be appointed following a call for applications by the Commission and a review of credentials by the Commission and a selection panel. The selection panel will comprise the Chair of the PMMRC, the Chair of the Working Group and a Commission representative. The Chair of the PMMRC will make the final decision on new Working Group members and the Commission's Board will be notified.
18. The PMMRC, in consultation with the Commission and the Working Group, appoints the Chairperson of the Working Group. The responsibilities of the Chairperson will include but are not limited to:
 - 18.1. Setting the meeting agendas.
 - 18.2. Finalising the meeting minutes and any written reports.
 - 18.3. Running the meetings.
 - 18.4. Facilitating the Working Group to achieve its functions.
 - 18.5. Making the final decision if the Working Group is not able to reach consensus.
19. Unless exceptional circumstances are identified and agreed upon by the Working Group and by the PMMRC, no member may hold office for more than six consecutive years. Such circumstances include an exceptional need for continuity of knowledge and skills, for example, if three or more members are leaving the Working Group at the same time. In such circumstances, a member's term may be extended for up to one year.
20. Every appointed member of the Working Group shall continue in office until their successor comes into office, unless in exceptional circumstances.
21. Any member of the Working Group may resign at any time by advising the Commission or the PMMRC in writing.
22. The Commission may, by written notice, terminate the appointment of a member or Chair of the Working Group.
23. The Commission and PMMRC may from time to time alter or reconstitute the Working Group, or discharge any member of the Working Group, or appoint new members to the Working Group for the purpose of decreasing or increasing the membership or filling any vacancies.

Management of Conflicts of interest

24. Management of Conflicts of Interest

- 24.1. Members must perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect the Working Group and its members and will ensure that it retains public confidence.
- 24.2. When members believe they have a potential conflict of interest on a subject that will prevent them from reaching an impartial decision or undertaking an activity consistent with the Working Group's functions, they must declare that conflict of interest and withdraw themselves from the discussion and/or activity.

Confidentiality

25. The maintenance of confidentiality is crucial to the functioning of the Working Group.
26. Members must note the statutory requirements in section 59E (6) of the Act, which prevents disclosure of information of the kind described in clause 3 of Schedule 5 of the act. Under this clause, information means any information that is personal information within the meaning of section 2(1) of the Privacy Act 1993; and that became known to any member or executive officer or agent of a Working Group only because of the Working Group's functions being carried out (for example, because it is contained in a document created, and made available to the member or executive officer or agent, only because of those functions being carried out), whether or not the carrying out of those functions is completed.
27. Members must note that the disclosure of information contrary to Schedule 5 of the Act is an offence and is liable on summary conviction to a fine not exceeding \$10,000 (s 59E(6)).

Meetings

28. The venue, timing and frequency of Working Group meetings will be coordinated with the Secretariat to fit within the allocated budget. It is expected that the Working Group will meet three times per year (one of these meetings will be via teleconference).
29. Members of the Working Group are entitled to actual and reasonable travel expenses. Members not employed by DHBs will be paid in line with the Cabinet Office Circular CO (12) 6 (Group 4, level 2). It is expected that members employed by DHBs will be supported by their DHB to attend Working Group meetings.
30. Travel costs, meeting fees, the meeting venue and catering for the meeting will be paid for out of the PMMRC committee meeting and fees budget.
31. The PMMRC National Coordinator will support the Working Group to ensure that a record of decisions is made, and that written advice is provided from the Working Group to the PMMRC through the PMMRC meetings. The Working Group will regulate its own procedures, according to State Service Commission requirements and guidelines,¹ to ensure that a record of decisions is maintained and is provided to the PMMRC meetings.

Communications

32. All media communication in relation to the work of the Working Group will be via PMMRC and the Commission. Working Group members will also adhere to the media requirement in the Commission's guidance document entitled "*Introduction to the Mortality Review Committees – A guide for committee members and advisors*".

Review

33. These terms of reference will be reviewed by the Commission and PMMRC two years from the date at which they are approved by the Commission.

¹ See: <https://www.ssc.govt.nz/sites/all/files/stat-crown-entities-guide-for-departments.pdf> for additional information.