



Terms of Reference

Parents Advisory Group (PAG)

Aim

The aim of the East Midlands Neonatal Operational Delivery Network (EMNODN) Parents Advisory Group (PAG), is to ensure that the parents and users of neonatal services in the EMNODN are involved as co-partners in the design and co-production of service delivery. The EMNODN PAG will be chaired by a parent representative who will represent the group by sitting on the EMNODN Board and advising the group on user issues relating to the maintenance, development and analysis of service standards within the EMNODN.

Membership

There is no minimum or maximum number of members, however each local neonatal parent support and involvement group, and Local Maternity and Neonatal System (LMNS) has the responsibility to agree and appoint parents to attend the group.

Membership comprises of the following;

- Parents/Carers who have received care in any of the EMNODN neonatal units
- Neonatal voices groups from the LMNSs within the East Midlands
- Parent champions/Family Integrated Care Link Nurses from each of the neonatal units within the EMNODN
- Ward Managers/Matrons from each of the Neonatal units within the EMNODN
- Director/Lead Nurse EMNODN
- Care Coordinator/Family Integrated Care Lead EMNODN

Remit

The PAG is a sub group of the EMNODN Board and represents the views of the local parent involvement groups in each of the EMNODN units and the LMNSs from within the East Midlands. The Group reports directly to the EMNODN Board through the Chair.

Members of the group may also sit on any ODN specific project groups to provide advice and the parental perspective

Objectives

- Review and co-creation of EMNODN strategies, projects, and initiatives, and non-clinical standards for neonatal care, in the context of local need and views of the families using the service. Advise the EMNODN Board of the likely impact on parents and families should the Network implement such initiatives.

- Review current service provision for parents and families and recommend changes in line with national strategy and guidance in order to ensure high quality care for babies and families.
- Identify key issues, such as access to services, local facilities, communication, equality and service development, making recommendations for changes across the network.
- Maintain contact with local parent support groups, and LMNS neonatal voices partnerships, to ensure that relevant, up to date feedback is provided
- Identify evidence of good local services for parents and families and promote these as exemplars for implementation across the EMNODN as appropriate.
- Review and revise all EMNODN parent and family informational literature, and communication technology to ensure fitness for purpose.
- Support EMNODN nursing and medical education programs by giving parent feedback at education events

Group Chair

The EMNODN PAG will have a Chair and Deputy Chair who are formally voted for by the membership of the group. The tenure for the Chair will normally be for a period of 3 years. This may be extended into further terms at the discretion and agreement by the membership, by way of a voting process.

It is the responsibility of the EMNODN Management Team to liaise with the Chair, and to ensure that agenda and minutes are circulated to the group, and that meetings are arranged with reasonable notice.

Voting

As a non-statutory group, there are no formal requirements for quoracy. Where consensus is required, this will be carried out by the majority of those who are in attendance at the meeting.

Meetings

Meetings will be held quarterly, with administrative support provided by the Network Office Manager.

Meetings will be face-to-face, at a venue central to the Network, with the ability for members who are not able to attend to dial in using Microsoft Teams.

Expenses

The EMNODN will reimburse parent members of the PAG for reasonable expenses incurred during the course of their activities as a member of the group. This will include travel and parking costs, and sustenance and hotel charges if an overnight stay is required.

All claims will need to be submitted using the [EMNODN Parent/Carer Expenses Claim Form](#).

PAG Parent Member Support

A support system is in place for all parent members of the group if required.

This comprises of the following;

Director/Lead Nurse EMNODN

Deputy Lead Nurse EMNODN

Care Coordinator/Family Integrated Care Lead EMNODN

LMNS Neonatal Voices Partnership

EMNODN PAG Chair and Vice Chair

Date ratified: October 2020

Date to be reviewed: October 2022