

THAMES VALLEY & WESSEX NEONATAL OPERATIONAL DELIVERY NETWORK

Parent Advisory Group (PAG)

Terms of Reference

1.0 Context

The Thames Valley & Wessex Neonatal Operational Delivery Network (TVW Neonatal ODN) supports the commissioning and provision of high quality, effective and affordable clinical care with equity of access across a managed clinical network.

The TVW Neonatal ODN Parent Advisory Group (PAG) will aim to ensure that the parents and users of neonatal services in Thames Valley & Wessex, Milton Keynes, South Wiltshire and West Sussex are involved as co-partners in the design and co-production of service delivery.

The TVW Neonatal ODN acts as a facilitator within a collaborative model where the commissioners remain accountable for commissioning of neonatal services and providers for the delivery of neonatal services. The TVW Neonatal ODN will ensure that the whole system works together to optimise high quality patient experience by bringing together patients, parents, commissioners, providers and other stakeholders in the design and delivery of consistent high-quality services.

The TVW Neonatal ODN reports to the NHS South Neonatal Programme Board through the Network Manager and Network Clinical Leads.

2.0 Purpose of the TVW Neonatal ODN Parent Advisory Group (PAG)

The purpose of the PAG is to ensure that the parents and users of neonatal services in the TVW Neonatal ODN are involved as partners in the design and co-production of service delivery and in the co-creation of products and resources designed to support current and former neonatal families.

Members are expected to represent the views and experiences of parents and families whose babies have been cared for in a neonatal unit and play a vital role in driving forward improvements and changes in neonatal care that provide the best quality service for patients.

The group will also be used as a forum for members to share best practice from respective local groups and initiatives such as mechanisms for peer support and engagement.

The aim of the group is to provide experience and advice on the parent perspective in all aspects of neonatal care in line with the recommendations for standards of neonatal care, DH Toolkit for High-Quality Neonatal Services (2009), NCCR (2019), GIRFT (2020) NICE Quality Standards Programme for Specialist Neonatal Care (2010) and the NHS Long Term Plan (2019).

3.0 Remit

The PAG is a subgroup of the TVW Neonatal ODN and represents the views of the local parent involvement groups in each of the TVW Neonatal ODN units and the LMNSs from within TVW. The Group reports directly to the TVW Neonatal ODN Management Team through the Chair.

Members of the group may also sit on any ODN specific project groups to provide advice and the parental perspective. All outcomes will be reported back to the PAG at the PAG meetings.

4.0 Objectives of the Neonatal PAG

- 4.1** The PAG is an integral part of the ODN structure and will be involved in the creation and implementation of the non-clinical aspects of the TVW Neonatal ODN work programme/NCCR Action Plan. PAG involvement will include:
- Oversight and parent voice input into any documents created
 - Attendance at project group meetings as a key member of that project team
 - Parent input into the direction and focus of a project
 - A parent voice will be heard regarding the implementation and communication of project outcomes.
- 4.2** Review and co-creation of TVW Neonatal ODN 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. PAG members would advise the TVW Neonatal ODN Management Team both directly and via the Family and Parent Engagement Lead regarding the impact on parents and families of the implementation of any national, regional and local initiatives.
- 4.3** Review current service provision for parents and families and recommend potential Network wide 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.
- 4.4** Maintain contact with local parent support groups, and LMNS Maternity Voices Partnerships, to ensure that relevant, up to date feedback is provided
- 4.5** Identify evidence of good local services for parents and families and promote them as exemplars for implementation across the TVW Neonatal ODN as appropriate.
- 4.6** Review and revise all TVW Neonatal ODN parent and family informational literature, and communication technology to ensure fitness for purpose.
- 4.7** Support the education of neonatal nursing and medical teams as well as wider groups where appropriate, regarding the impact of the neonatal experience on families during their time on the neonatal unit and beyond.
- 4.8** Link with all ODN subgroups to ensure the neonatal parent voice is heard within these settings.

- 4.9** Where the PAG identify a gap in service or information impacting on the family experience they will raise this through the PAG group meeting and will lead work on improving this area with the full support of the TVW Neonatal ODN Management Team.

5.0 Chair & Meeting arrangements

- 5.1** The PAG will be chaired by the Network Family and Parent Engagement Lead who will represent the group by attending the TVW Neonatal ODN Clinical Forum and Governance meetings, and other Network Subgroup and Working Group meetings.
- 5.2** The PAG will be a predominantly virtual group with occasional 'face to face' meetings as agreed by the group members with consideration of the large geography of the ODN and PAG volunteer giving up their own time.
- 5.3** The PAG will meet every 2 months (with the FI Care Group meeting in the alternate months). Meetings will be in the main carried out via MS Teams and additional meetings may be arranged 'ad hoc' when required to offer timely resolution to an urgent issue. These will be called by the group Chair and or TVW Neonatal ODN Manager.
- 5.4** Meeting agendas, documents and minutes will be provided by the TVW Neonatal ODN Project Support Officer. This includes:
- Preparing agendas
 - Preparing meeting notes and information

6.0 Thames Valley & Wessex AHP Group Membership

- 6.1** The aspiration is to have widely representative members with links to each of the neonatal units within the TVW region. There is no minimum or maximum number of members or meeting attendees required to make a meeting quorate.
- 6.2** Membership comprises of the following:
- Parents / Carers who have received care in any of the TVW Neonatal ODN neonatal units, 12 months since discharge from a unit, to ensure psychological safety, to 5 years postnatally
 - TVW Neonatal ODN Family and Parent Engagement Lead
 - Neonatal voices groups from the LMNSs within TVW, via Maternity Voices Partnerships (MVP's) or MNVP's (as required)
 - TVW Neonatal ODN Care Coordinators / FI Care Leads (as required)
 - TVW Neonatal ODN Psychologist (as required)
- 6.3** Continued recruitment. Part of the PAG role is to support continued recruitment into each locality of the TVW region. The PAG will work together with the TVW Neonatal ODN to ensure strategies of recruitment are regularly reviewed and there is a continued drive to recruit to the group for

members; mothers/birthing people, fathers/non-birthing partners, carers and grandparents are welcomed from a variety of backgrounds to encourage inclusivity.

Lead and Local Care Coordinators will maintain a link with units across the region to identify potential members.

Social media and links to other volunteer groups and peer support groups will be utilised to access wider groups of neonatal families to ensure the PAG remains representative.

A link will be made to the local MVP's that cover the same areas as the PAG, to ensure MVP groups are aware of the expertise of the PAG and utilise this link to provide representative responses to any neonatal specific queries nationally. It is important to have this joined up approach to enable a seamless journey for neonatal parents, and this overlaps with the maternity postnatal pathway.

7.0 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 or those who have commented on documents under review on the Future NHS Platform.

8.0 PAG Member Support

A support system is in place to support parent representatives in the delivery of their duties. This includes:

- PAG induction

- Support and signposting by Network Psychologist and Local Care Coordinators to support the parents as and when they need this

- Training if required for specific work

9.0 Communication

Communication within the group will take a number of forms:

- Family and Parent Engagement Lead nhs.net email

- WhatsApp Group

- Future NHS Platform

- Closed Facebook Group

- Open Facebook Group

10.0 Review of Governing Documents

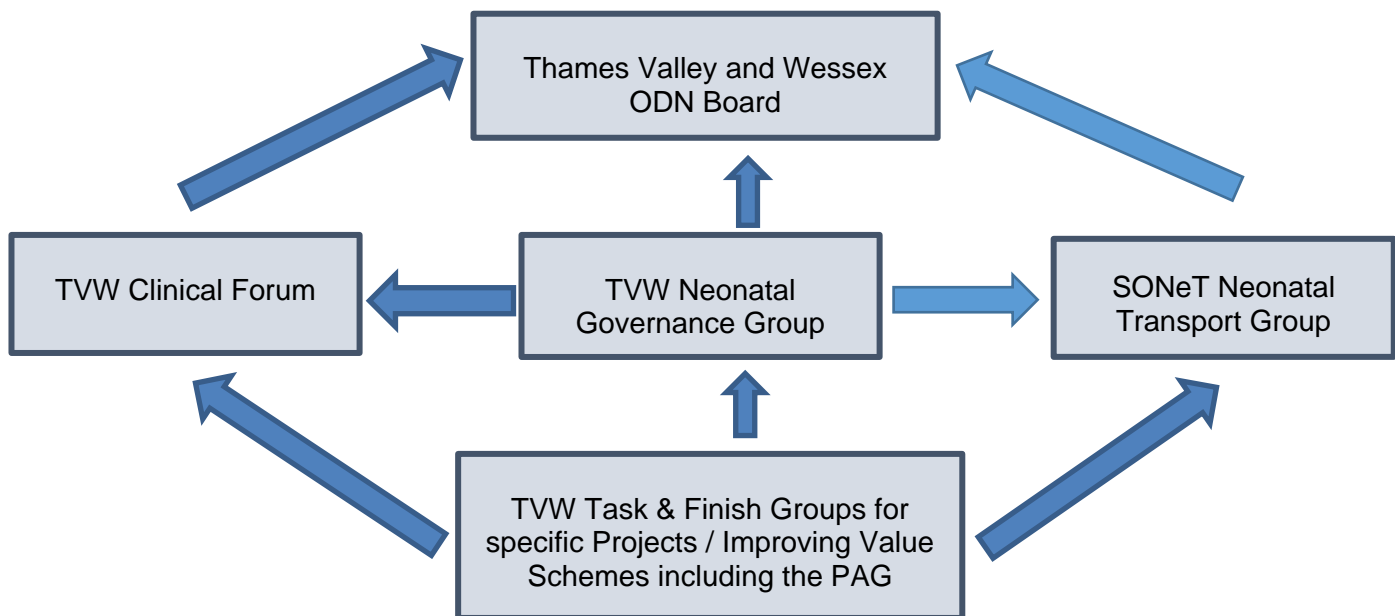
In order to ensure that the advisory groups are best configured to meet the changing needs within TVW these terms of reference and other governing documents will be reviewed by the PAG and endorsed by TVW Neonatal ODN Governance Group every three years or earlier if local or national change necessitated earlier review.

Agenda will be sent out/added to Future NHS platform one week prior to the meeting with meeting notes being sent out/added to Future NHS platform within two weeks of the meeting being held.

For confidentiality and confidence within the group any discussions that occur during meeting will not be taken outside of the meeting without prior permission.

The Terms of Reference will be reviewed every three years unless any changes need to be made.

Thames Valley and Wessex Neonatal ODN Governance Structure



TVW working group

- Lead Nurses and Practice Educators Leads
- AHP working group
- Breast Feeding
- Hospital At Home Outreach
- Family Centred Family Integrated Care
- Palliative Care
- Neonatal Perinatal Mental Health Group
- Parent Advisory Group
- Parent Passport Group
- Repatriation Group

Version Control:

Version	Date	Details	Author(s)	Comments
Version 1	19.10.2021	Creation of Terms of Reference	Co-produced by EJ, LL, SE, CL, GO	Ratified December 2021 Governance meeting
Ratified by:	Governance Forum December 2021			
Review date:	December 2024			