



**Newborn Brain Care**

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# Terms of Reference

**Newborn Brain Care Group**

A Special Interest Group of the



**British Association of  
Perinatal Medicine**

## General

The Newborn Brain Care group (NBC) is a Special Interest Group of the British Association of Perinatal Medicine (BAPM). As a BAPM Special Interest Group, NBC follows BAPM's governance and processes at all times, including rules on elections, committee membership and the production of guidance.

## Mission Statement

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*Optimising newborn brain health for lifelong benefit*

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## Background

Brain injury remains one of the major unsolved problems in neonatal care, with survivors at high risk of lifelong neurodisability. Among infants admitted to neonatal units, the most common disorders associated with development risk are neonatal encephalopathy and perinatal arterial ischaemic stroke in term infants, and the consequences of germinal matrix–intraventricular haemorrhage and white matter injury in extremely preterm infants. These outcomes place an enormous physical, psychological and financial burden on individuals, families and society.

While the past four decades have seen dramatic improvements in neonatal survival, the incidence of cerebral palsy and other neurodevelopmental problems remains high in these infants. No single intervention can ameliorate neonatal brain injury, given the complex interaction between ex-utero brain development, pathological processes, developmental trajectory, genetic susceptibility and environmental influences. However, a coordinated, interdisciplinary approach to early detection, diagnosis and treatment of neurological injury alongside enhanced development-sensitive clinical care offers the best opportunity for improving outcomes and facilitating new lines of neuroprotective research.

The neonatal neurocritical care model of service delivery has gained considerable traction internationally over the past decade. In North America, the Neuro-Intensive Care Nursery model has been established since 2008, with a growing number of units worldwide adopting this approach. North America has also led the way with the establishment of the Newborn Brain Society ([www.newbornbrainsociety.org](http://www.newbornbrainsociety.org)) (NBS) and accredited Neonatal Neurocritical Care Fellowship Training Programmes. There is currently significant variability in clinical practice within and between neonatal units across the United Kingdom in the management of infants at risk of neonatal brain injury and those with neurological problems. NBC aims to address this by promoting brain-orientated care in all neonatal units, including special care baby units, local neonatal units and neonatal intensive care units.

## Vision

NBC's vision is to promote evidence-based, consistent and equitable brain-orientated care for all infants admitted to a neonatal unit in the United Kingdom. The group seeks to do so by (1) raising the profile of newborn brain care as a core component of neonatal practice, (2) promoting subspecialty interest among trainees, (3) supporting multidisciplinary education and training, and (4) facilitating research and innovation that translates into improved outcomes for infants and their families.

## Scope

Newborn brain care encompasses a multidisciplinary approach to protecting the developing brain as well as the diagnosis and management of congenital and acquired brain injury in the neonatal period in order to optimise an infant's developmental potential. The NBC group recognises four inter-related pillars of newborn brain care:

- Assessment – structured neurological examination, neurobehavioral assessment and clinical evaluation.
- Monitoring and imaging – neuromonitoring including amplitude integrated electroencephalography (aEEG) and EEG, near-infrared spectroscopy (NIRS), cranial ultrasound and magnetic resonance imaging (MRI).
- Protecting – neuroprotective strategies including therapeutic hypothermia, care bundles to prevent intraventricular haemorrhage, and optimisation of the NICU environment.
- Developing – developmental care, family-integrated care, and supporting the parent–infant relationship during the neonatal period.

The network's scope extends across all levels of neonatal care, from special care baby units through to regional neonatal intensive care units, with the aim of ensuring equitable access to high-quality brain-orientated care regardless of the unit in which an infant is cared for.

## Membership

NBC membership is a benefit of BAPM membership, and all NBC members must maintain their BAPM membership to remain in the group. If any member of the NBC Executive Committee or a workstream does not retain their BAPM membership, they must immediately step down from their role.

NBC group members are professionals with an interest in brain-orientated neonatal care. The group welcomes professionals in neonatology, paediatric neurology, fetal medicine and obstetrics, neurophysiology, neuroradiology, neurosurgery, nursing and midwifery, allied health professions, psychology, and clinicians in training. Representation from families and relevant charities and organisations are also welcome.

BAPM will maintain a database of members signed up to the NBC and can provide a list of names, roles and place of work on request.

## Responsibilities

1. To promote evidence-based brain-orientated care in all neonatal units across the United Kingdom.
2. To set standards in clinical practice that optimise neurodevelopmental outcomes for newborn infants.
3. To distinguish between established clinical practice and areas with a limited evidence base, and to support the generation of evidence where it is lacking.
4. To facilitate equitable, high-quality newborn brain care across all neonatal networks and unit levels.
5. To facilitate multidisciplinary education and training in newborn brain health for medical, nursing and allied health professionals.
6. To support curriculum development in fetal and neonatal neurology and promote subspecialty interest among trainees.

7. To enhance the individual and family experience through promotion of family-integrated and developmental care.
8. To generate new knowledge in neonatal neuroscience and support research into new interventions.
9. To encourage the next generation of neonatal neuroscientists and clinicians with an interest in newborn brain care.
10. To collect and utilise standardised datasets for audit, benchmarking and research.
11. To liaise with national bodies including the National Neonatal Audit Programme, NHS England, Operational Delivery Networks, and relevant professional societies.
12. To collaborate with international groups and networks engaged in neonatal neurocritical care, such as the NBS.

## Structure

The founding organisational structure of the NBC group consists of an Executive Committee and four workstreams.

### Executive Committee

The Executive Committee (EC) is a **multidisciplinary group** that acts on behalf of all NBC members. It is linked to the BAPM Executive Committee and work programme and liaises with external bodies and families as required.

Election to the Executive Committee follows standard BAPM procedures for election to Special Interest Groups. The BAPM office will support NBC to run elections each Spring for any committee positions that are open for that year. Each Executive Committee member serves for a term of three years and may be re-elected for one further term.

The EC consists of:

- Five officers: Chair, Vice-Chair, Treasurer, Secretary and Communications Officer
- The leads of each of the four workstreams
- A trainee representative
- A family representative

Additional members may be invited on an ad hoc basis to ensure a balanced representation of families, healthcare professionals and relevant disciplines.

### Officers' Roles

**Chair:** NBC lead with a strategic role. Suggests and follows through actions from meetings and workstreams. Chairs the Committee meetings, ensures responsibilities are on track, and liaises with individual members, BAPM and other relevant organisations.

**Vice-Chair:** Deputises for the Chair in their absence. Represents NBC on external forums and liaises directly with incoming communication via BAPM and other channels.

**Treasurer:** Responsible for the finances of any revenue-generating activities (such as conferences). Day-to-day bookkeeping and budgeting should be undertaken by the Treasurer with sight of the rest of the EC. Income generated by NBC will be held by BAPM in a restricted fund as part of the BAPM accounts. Budgets for paid events must be shared with BAPM before any funds are committed or the event is advertised. It is expected that any profits from activities will be used for further educational and training purposes relevant to NBC.

**Secretary:** Responsible for the programming and timely running of Committee meetings. Duties include taking, formatting, amending and distributing minutes, circulating relevant documents

among Committee members, and liaising with BAPM for these purposes.

**Communications Officer:** Responsible for promoting activities within NBC, compiling 3 newsletters/year which will be distributed to BAPM members via the BAPM office and responsible for communication across relevant social media channels.

## Workstreams

NBC operates through four workstreams, each led by an elected lead responsible for planning, running and executing projects approved by the EC. Recruitment to workstream leadership positions should follow the BAPM working group recruitment process, which uses open adverts, gives preference to BAPM members and reviews applications anonymously. Workstreams operate with input from across the group, and there is no limit on the number of members per workstream.

### 1. Clinical Practice

The Clinical Practice workstream is responsible for:

- Promoting evidence-based clinical practice in newborn brain care across all neonatal unit levels.
- Developing and disseminating standardised clinical protocols and care bundles.
- Setting standards for neuromonitoring, neuroimaging and neurological assessment.
- Surveying current practice across the UK to identify variability and areas for improvement.
- Facilitating equitable access to therapies including therapeutic hypothermia and neuroprotective interventions.
- Promoting developmental care, family-integrated care and the optimisation of the neonatal environment.

### 2. Education and Training

The Education and Training workstream is responsible for:

- Organising and delivering educational events including an annual study day.
- Facilitating multidisciplinary training in newborn brain health for medical, nursing and allied health professionals across all neonatal unit levels.
- Reviewing and contributing to the RCPCH curriculum and supporting non-curriculum educational programmes.
- Promoting subspecialty interest in newborn brain care among trainees.
- Compiling and sharing educational resources, case studies and examples of good practice.
- Providing guidance and support to families.

### 3. Research and Innovation

The Research and Innovation workstream is responsible for:

- Identifying key knowledge gaps in neonatal neuroscience and newborn brain care.
- Setting a national research agenda for newborn brain care.
- Supporting and facilitating multicentre research and clinical trials.
- Encouraging the next generation of neonatal neuroscientists through mentorship and collaboration.
- Supporting the dissemination of research findings to NBC group members and the wider community.
- Promoting innovation in neuromonitoring, neuroimaging and neuroprotective therapies.

### 4. Data

The Data workstream is responsible for:

- Developing and promoting the use of standardised and harmonised datasets for newborn

brain care in line with NHS information governance standards.

- Liaising with the National Neonatal Audit Programme and other local, regional and national audit programmes.
- Supporting Operational Delivery Networks and neonatal units in accurate and complete data collection.
- Facilitating data analysis, benchmarking and dissemination of findings.
- Supporting the creation of national and international data repositories to evaluate the benefits of brain-orientated care.

### Additional Roles

**Trainee Representative:** The trainee representative represents UK neonatal trainees and provides a trainee perspective, advising on education, training and curriculum development in fetal and neonatal neurology; contributing to policy, guidance development; and working with workstream leads on common projects.

**Family Representative:** Provides a parent perspective and ensures that families' views are heard and taken into consideration in decision-making. The family representative liaises with other parent members and with workstream leads on common projects.

### Communications

NBC has a responsibility to communicate with the wider membership beyond the Executive Committee. The group will produce newsletters three times per year, providing content to the BAPM office for distribution to the NBC mailing list. The BAPM office can also share news and events from NBC to the full BAPM mailing list through the regular monthly and events newsletters.

NBC will be given a section on the BAPM website, maintained by BAPM Head Office. Should NBC wish to set up a dedicated email address or social media accounts, the communications officer of NBC will be tasked with monitoring these on a regular basis, and log-in details must be shared with the BAPM office.

### Committee Meetings

- Quorum: a quorum of eight members is required for Executive Committee meetings (including chair or vice-chair).
- When a workstream lead cannot attend, another member from that workstream should deputise. Non-attendance at more than two consecutive meetings without reasonable explanation will lead to review of the member's position on the EC.
- Guest experts may be co-opted when specific items of interest are being discussed.
- The EC will meet monthly during the establishment phase, moving to quarterly meetings once established.
- Communications may be circulated between meetings via BAPM as needed.
- Meetings will be held virtually or face-to-face and will last no longer than two hours.
- Workstream meetings will be held quarterly, with provision for extraordinary meetings as required.
- Normally the NBC Secretary organises meetings from their own accounts. The BAPM office can set up meetings if required but this should not be relied upon on a frequent basis.

### Annual Work Plan

An NBC representative will be invited to attend the December BAPM Executive Committee meeting each year to contribute to discussions about BAPM's work plan and to present a work plan for NBC for the upcoming year. This is to ensure that the BAPM office and NBC are working in synergy and without overlap. Plans should be realistic, taking account of the capacity of volunteers and the BAPM

office to support work. NBC will also provide an interim report in writing to the BAPM Executive Committee meeting in June.

## Producing Guidance and Standards

NBC may produce educational resources, toolkits and practical guides independently, but a scoping document must be signed off by the BAPM Publications Committee before work begins. The Publications Committee meets on a quarterly basis.

If NBC wishes to produce frameworks for practice or staffing standards, this must be done in partnership with BAPM Head Office and topics will be prioritised through the usual process of the BAPM Publications Committee. The BAPM office can offer support with graphic design and consultation when the text is fully completed.

## Finances

NBC should cover its own costs. Income may be generated by events, including sponsorship of events. Any sponsorship must be in line with BAPM's policy for interaction with partner companies. BAPM Head Office is able to pay expenses and invoices and hold money for the NBC in a restricted fund as part of the BAPM accounts. Day-to-day bookkeeping and budgeting should be undertaken by the Treasurer with sight of the rest of the EC. Budgets for paid events must be shared with BAPM before any funds are committed or the event is advertised.

## Events

The organisation of events should be undertaken by NBC members. BAPM office staff will likely not be able to attend live events but can advise and provide templates to assist with event management. Registration for paid events can be taken through the BAPM office.

For webinars, BAPM will aim to support NBC to run one to two jointly organised webinars per year, with BAPM setting up and advertising the event, taking bookings, sending links and gathering feedback. NBC may also run its own webinars, but arrangements should be made to ensure only BAPM members can attend, with the exception of one to two open events per year.

## Endorsement

BAPM SIG's receive frequent requests to endorse documents, research studies or training courses. Any requests for endorsement can be referred to BAPM Head Office in the first instance. Should NBC wish to establish a process to provide endorsements under specific circumstances in its area of expertise, this must be agreed with the BAPM Executive Committee.

## Accountability

NBC is accountable to the BAPM Executive Committee and to the BAPM membership.

## Affiliations

NBC will seek to collaborate with relevant professional bodies and networks, including but not limited to the British Paediatric Neurology Association (BPNA), the British Maternal and Fetal Medicine Society (BMFMS) and international groups engaged in neonatal neurocritical care such as the NBS. The group will also liaise with the British Association for Neonatal Neurodevelopmental Follow-Up (BANNFU) SIG to ensure complementary and coordinated activities.



## **Confidentiality**

Documents circulated by BAPM and via the Secretary, and minutes from meetings, may be shared externally via BAPM unless expressly stated as confidential or in draft form.

## **Changes to Terms of Reference**

Changes to the terms of reference may be agreed by a majority vote of the Executive Committee. The terms of reference will be reviewed in full every three years from the date of adoption.

## Members in Present Roles

Role	Name
Chair	<i>TBC</i>
Vice-Chair	<i>TBC</i>
Treasurer	<i>TBC</i>
Secretary	<i>TBC</i>
Communications Officer	<i>TBC</i>
Clinical Practice Lead	<i>TBC</i>
Education & Training Lead	<i>TBC</i>
Research & Innovation Lead	<i>TBC</i>
Data Lead	<i>TBC</i>
Family Representative	<i>TBC</i>
Trainee Representative	<i>TBC</i>