



**BANNFU**



## **British Association for Neonatal Neurodevelopmental Follow-Up (BANNFU)**

### **Terms of Reference**

#### **General**

The British Association for Neonatal Neurodevelopmental Follow-Up (BANNFU) is a Special Interest Group of the British Association for Perinatal Medicine.

#### **Statement**

We believe that every baby discharged from a Neonatal Unit in the UK has the right to a purposeful comprehensive medical and developmental service that addresses their needs, from discharge for as long as they need, and every neonatal unit in the UK should be able to use this information as evidence for planning and delivering the best possible neonatal care to future babies and families.

#### **Vision**

BANNFU's vision is to ensure that the best neurodevelopmental follow up service is available for all babies discharged from Neonatal Units at least until school age, by raising the profile of clinicians involved, monitoring the provision of care, supporting the data collection process, and facilitating the benchmarking of NICUs performance as well as promoting best practice.

#### **Membership**

BANNFU members are professionals or families with some association to neonatal units. We welcome professionals in Neonatology, Paediatrics, Nursing and midwifery, Obstetrics, Fetal Medicine, Allied Healthcare Professionals, Psychology, Psychiatry, Clinicians in training, former patients and families, as well as charities and other relevant organisations.

Healthcare professionals must have a BAPM or BACCH membership

#### **Responsibilities**

1. To share best practices on neonatal neurodevelopment, with local clinicians
2. To advise on early interventions in the unit or after discharge, that may improve early childhood outcomes
3. To provide guidance to clinicians and families on neonatal neurodevelopmental follow-up
4. To advocate for high-risk babies discharged from a neonatal unit to have formal neurodevelopmental follow-up
5. To monitor compliance with the recommended guidance on neurodevelopmental service by surveying local practice



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6. To ensure an updated outcomes' record form is available on the online platforms accessible to local clinicians
7. To collaborate with local, regional and national audit programmes on improving the capturing of data.
8. To recommend that every Neonatal Network has a Follow Up Coordinator responsible for supporting the service provision in the area, and ensuring data collection.
9. To support the analysis of information entered on the outcome's forms
10. To raise the profile of clinicians and families providing developmental follow up care by organising and supporting educational events.
11. To facilitate communication between teams and encourage sharing of best practice
12. To contribute to and facilitate collaboration in research and development in follow-up methodology and outcomes.
13. Future plan: To raise awareness about the skills that babies discharged from neonatal units need for school readiness and school entry, and to encourage liaison between health and educational services

### **Structure**

The organizational structure of BANNFU consists of an Executive Committee (EC) and four workstreams.

#### **1- Executive Committee (EC)**

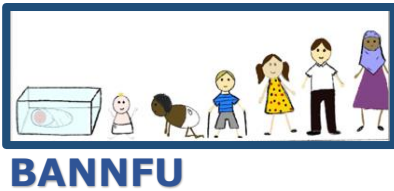
The EC is a multidisciplinary group of members that acts on behalf of all members of BANNFU. It feeds into the BAPM Executive Committee and work programme and liaises with external bodies and families as required.

The EC consists of Three officers - President, Chair, Secretary – a BAPM representative, the leads of the four workstreams, a parents' representative and a patients' representative. Additional members are invited on an ad hoc basis to ensure that a balanced mix of families and healthcare professionals is represented.

Committee members are elected by the Executive Committee for a term of 3 (three) years, and they can also be re-elected for a second term.

#### **Officers' Roles**

**President:** BANNFU's image and voice on external forums. Liaises directly with incoming communication via BAPM and other channels. Deputises for the Chair in their absence.



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**Chair:** BANNFU 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.

**Secretary:** Responsible for the programming and timely running of the Committee meetings. Duties include taking, formatting, amending and distributing minutes, circulating relevant documents amongst members of the Committee, and liaising with BAPM for these purposes.

#### Website and Newsletter

The secretary, or a voluntary member of the committee will be responsible for liaising with the BAPM representative for the update of the website and the periodical newsletter (3 monthly)

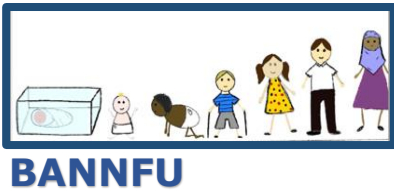
## 2- Workstreams

Workstreams are Education & Training, Research, Service Provision & Data Management. Each workstream has an elected Lead responsible for the planning, running, and with the support of other streams, the executing of projects approved by the EC. Workstreams work independently from each other and there is no limit on the number of members per workstream. Parents and patients are encouraged to join their workstream of interest.

### 2.1 Education and Training Workstream

The Education and Training Workstream functions are :

- To organize and deliver the BANNFU Annual Study Day. This is a multi-professional, family and former patient inclusive education day aimed at raising awareness, measuring, and analysing outcomes of the interventions that high-risk babies and families experience in neonatal units and after discharge
- To Compile resources to aid neurodevelopmental follow-up, including developing resource of case studies for neurodevelopmental follow-up that showcase good practice
- To signpost in the newsletter other educational events that may be relevant to
- neurodevelopment
- To develop guidance and support for neonatal trainees with a neurodevelopmental interest
- To share guidance and support to families



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#### 2.2 Clinical Service Provision Workstream

The Clinical Service Provision aims at referencing and monitoring the service provision to all babies at high risk of developmental problems in the UK from delivery to up to the age of two years in the first instance. The workstream will do this by :

- Promoting the provision of a comprehensive neurodevelopmental care service that meets the needs of families and babies
- Monitoring the quality of the service by surveying local practices on a regular basis
- Facilitating outcome documentation on electronic records attached to the baby's NHS number/Badger system- by updating the BANNFU outcomes forms making them suitable for data entry at any given clinical encounter
- Recommending and encouraging training on neurodevelopment and early intervention
- Liaising with the Education stream (study days and training courses)
- Liaising with the patients' and parents' leads for ideas on improvement of care and service provision

#### 2.3 Data Management Workstream

The Data Management workstream has the following functions :

- To Liaise with NNAP and other Local, regional or national audits
- To Provide support to ODNs and neonatal units by liaising with the local care coordinators, to ensure that the data that is collected is accurate and complete
- To be actively involved in data analysis and dissemination

#### 2.4 Research Workstream

The Research Workstream has the following objectives :

- To identify and highlight the key knowledge gaps in neonatal neurodevelopmental care
- To provide advisory support for researchers conducting neonatal neurodevelopmental research
- To support the dissemination of key research findings to BANNFU members



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#### **3- Additional Roles**

- **Parents' Representative:** Provides a parent perspective and makes sure that parents' views are heard and taken into consideration in decision-making. The Lead of the parents' group liaises with other parents, members of BANNFU on a regular basis to seek their views and get them involved in workstreams.
- **Patient Representative** Provides a patient perspective and makes sure patients are heard and taken into consideration in decision-making. The Lead for the patients' group liaises with other patients members of BANNFU, with the Lead of the parents' group and with other workstreams' Leads for common projects. Patients are invited to join the workstream of their choice.

#### **Committee meetings**

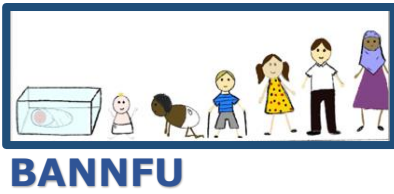
- Quorum - There will be a quorum of seven (7) on the EC
- When the workstream lead cannot attend an EC meeting, then another member from that workstream should deputise. Non-attendance to more than two consecutive meetings without reasonable explanation will lead to automatic destitution of the member from the EC and election of a new member
- Guest experts may be co-opted when specific items of interest are being discussed
- The EC will meet monthly initially, then every 3 months
- Member communications may be sent out between meetings via BAPM if needed.
- Meetings will be virtual or face to face and will last no longer than 2 hours.
- Workstream meetings are 4 a year and there may be the need for extraordinary meetings

#### **Accountability**

BANNFU responds to the BAPM Executive Committee and is accountable to the BAPM membership.

#### **Confidentiality**

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



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#### Changes to Terms of Reference

Changes to the terms of reference can be agreed by a majority vote of the committee. The terms of reference are reviewed in full every 3 years from September 2021.

#### Members in present roles

President	Dr Angela Huertas
Chair	Dr Anusha Arasu
Secretary	Dr Angela D'Amore
BAPM representative	Ms. Kate Dinwiddy
Leads for Education and Practice	Dr Fran O'Brien and Dr Pip Chisholm
Leads for Clinical Service and Data	Dr Angela Huertas and Dr Anthony Kaiser
Leads for Research	Dr Naz Merchant and Dr Hilary Wong
Parents' representative	Ms. Laurence Galland
Former patients' representative	<i>TBA</i>
Current AHP additional members	Prof Sam Johnson (Professor in Psychology) Dr Betty Hutchon (Consultant Developmental Therapist)
Lead for Website and Newsletter	Dr Edit Fukari