

Transition from Neonates to Paediatrics Framework Working Group - Terms of Reference

Purpose

This document outlines the terms of reference for a BAPM working group to develop a Framework for Practice on the Transition of care from Neonates to Paediatrics.

Background

13.4% babies born at <28 weeks' gestation and 4.8% of all neonatal unit (NNU) graduates are admitted to paediatric intensive care units (PICU) within the first two years of life. Approximately half the children admitted to PICU under 2 years of age are neonatal graduates, a third of them are admitted more than once. These babies form a subset of NICU graduates that require significant ongoing General and Subspeciality Paediatric care. Additionally, these figures reflect increasing numbers of children transferred directly to PICUs and Paediatric wards with technology dependency and complex conditions following neonatal care.

Neonatal and paediatric critical care is delivered in network models in England and Wales across 169 NNUs and 24 paediatric intensive care units. Babies may be cared for in neonatal units or paediatric critical care units close to home or further away in another region. For babies transitioned from neonatal to paediatric care, high quality holistic care is dependent on relevant clinical and other information being shared with the receiving clinical teams.

This working group will collaborate across neonatal and paediatric services to develop a framework for safe and effective transition of care from neonatal to paediatric services to meet the needs of this group of babies with increasingly complex health care needs. This includes:

1. Inpatient transition to specialist paediatric services (e.g., PICU, long-term ventilation, gastroenterology etc)
2. Inpatient transition to local secondary paediatric services
3. Transition to outpatient paediatric services of babies with long term needs/ medical complexity

This document will not include palliative care pathways or specific clinical pathways relating to single conditions, e.g. congenital cardiac surgery.

Group Outputs

- A Framework for Practice
- Parent Leaflet

Group Members:

Chairs: Rum Thomas (BAPM, PCCS) and Timothy Watts (BAPM, RCPCH)

- Parents or carers of NNU graduates previously transferred to paediatric services
- 1 NICU LNU SCU Consultant
- 1 General Paediatrician
- 1 HDU Paediatrician or PICU Consultant
- Paediatric Subspeciality consultant (e.g., Respiratory, Gastroenterology)
- 2 Postgraduate doctors in training (one neonates, one paediatrics)
- 3 Nurses (one neonates, one paediatrics, one complex care planning / discharge neonatal or paediatrics)

- 1 Dietician
- 1 Occupational Therapist or Physiotherapist
- 1 Speech and Language Therapist
- 1 Psychologist
- 2 Network Managers / Directors (neonatal and paediatric)

Stakeholder Groups

- Royal College of Paediatrics and Child Health – Timothy Watts
- Paediatric Critical Care Society – Rum Thomas
- British Association of Paediatric Surgeons
- Bliss
- British Paediatric Respiratory Society
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Neonatal Nurses Association
- British Paediatric Neurology Association
- British Cardiovascular Society
- Association for Paediatric Palliative Medicine
- Neonatal Transport Group

Meetings

It is envisaged that this work will take approximately 8 months and involve 6 virtual meetings. Parents and carers will not be expected to attend all meetings. Following completion of a draft Framework for Practice agreed by the working group, there will be a period of consultation with BAPM membership and relevant stakeholders before the final document is published on the BAPM website. It is expected that the Chairs of the working group and/or other members will participate in an educational webinar to publicise the final Framework for Practice.

Expected Timetable

Please note that BAPM working groups are run and managed by volunteers so dates may be changed if work or personal circumstances make this unavoidable.

| Milestones | Date |
|---|------------|
| Meeting 1 - Intros and scope (60 mins) | 15/10/2024 |
| Meeting 2 - contents and responsibilities (90 mins) | 11/11/2024 |
| Meeting 3 - Check in, troubleshooting (60-90 mins) | 17/12/2024 |
| Meeting 4 - Review of first draft (60-90 mins) | 17/01/2025 |
| Meeting 5 - Review of second draft (60-90 mins) | 21/02/2025 |
| Meeting 6 - post consultation (60-90 mins) | TBC |
| Publication and webinar | TBC |

Responsibility and Accountability

The group is responsible to the BAPM Executive Committee and accountable to the BAPM membership.