

Transition from neonatal to paediatric care for babies with long term or complex healthcare needs: BAPM framework for practice 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 and scope

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 and their families. 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 at high risk of further inpatient care in paediatric services due to their long term needs or medical complexity

This document will not include palliative care pathways or specific clinical pathways relating to single conditions e.g., congenital cardiac surgery. This will also not include babies who are transferred from NICU to specialist paediatric services and back to paediatrics.

Group Outputs

- A Framework for Practice
 - To potentially include signposting for support for multi-disciplinary health care professionals
- Parent Leaflet
- Audit tool

Group Members:

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

- Dr Victoria Puddy, NICU Consultant

- Dr Peter Davis, PICU Consultant
- Dr Damien Armstrong, General Paediatrician
- Dr Stuart Wilkinson, Respiratory Paediatrician
- Dr Shil Patel, PICU Resident
- Dr Rachael Fleming, NICU Resident
- Saskia Scriven, Advanced Neonatal Nurse Practitioner
- Jennifer Webb, Lead PICU Nurse
- Melissa Huish-Davis, Neonatal Discharge Planning Nurse
- Rachel Pountney, Dietician
- Alice Gair, Occupational Therapist
- Marina Sloan, Speech and Language Therapist
- Rachel Calvert, Clinical Psychologist
- Liz Langham, Neonatal and Paediatric Network Director
- Dr Sarah Seaton, Epidemiologist

Parent and Carer Input

A separate parent/carer engagement group will be formed and curated by BAPM. It is envisaged that they will contribute to content and to review the draft framework through written and face to face feedback.

Stakeholder Groups

- Royal College of Paediatrics and Child Health – Timothy Watts
- Paediatric Critical Care Society – Rum Thomas
- Neonatal Nurses Association
- Neonatal Transport Group
- Paediatric Critical Care Acute Transport Group
- Bliss
- WellChild
- British Association of Community and Child Health
- British Association of Paediatric Surgeons
- British Paediatric Respiratory Society
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- British Paediatric Neurology Association
- British Cardiovascular Society
- Association for Paediatric Palliative Medicine
- Royal College Physiotherapists
- Royal College Occupational Therapists
- Royal College Speech and Language Therapist
- Neonatal Dieticians Special Interest Group
- Neonatal and Paediatric Pharmacy Group (NPPG)
- British Psychological Society and Association of Clinical Psychologists

Meetings

It is envisaged that this work will take approximately 9 months and involve approximately 6 virtual meetings. Parents and carers will not be expected to attend 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)	31/10/2024
Meeting 2 - contents and responsibilities (90 mins)	11/11/2024
Meeting 3 - Check in, troubleshooting (60-90 mins)	17/12/2024
Meeting 3b – Check in, progress review of first draft (60 mins) - review closer to the time	17/01/2025
Meeting 4 - Review of first draft (60-90 mins)	21/02/2025
Meeting 5 - Review of second draft (60-90 mins)	March TBC
Consultation Webinar	TBC
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.