British Association of Perinatal Medicine

Transition from neonatal to paediatric care for babies with long term or complex healthcare needs

A BAPM Framework for Practice

April 2026

Contents

Endorsed by

In partnership with

Members of the working group

Dr Rum Thomas (Chair), Consultant in Paediatric Intensive Care Medicine, Sheffield Children's NHS Foundation Trust; Clinical Lead (South), Yorkshire & Humber Paediatric Critical Care Operational Delivery Network
Dr Timothy Watts (Chair), Consultant Neonatologist, Evelina London Neonatal Unit, Guy's & St Thomas' Foundation Trust; Joint Clinical Lead, South London sector, London Neonatal Operational Delivery Network
Dr Damien Armstrong, Consultant Paediatrician, Altnagelvin Hospital, Derry, Northern Ireland
Dr Rachel Calvert, Principal Clinical Psychologist, Sheffield Children's NHS Foundation Trust
Dr Peter Davis, Consultant Paediatric Intensivist, Bristol Royal Hospital for Children; Clinical Director, South West Paediatric Critical Care Operational Delivery Network
Dr Rachael Fleming, Neonatal Subspecialty Trainee, NHS Greater Glasgow and Clyde
Alice Gair, Advanced Neonatal and Paediatric Occupational Therapist and Allied Health Professional Fellow, Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust
Denise Hart, Lead Physiotherapist, Thames Valley & Wessex Neonatal Network
Melissa Huish-Davies, Neonatal Discharge & FiCare Co-ordinator Nurse, University Hospital for Wales
Elizabeth Langham, Neonatal, Paediatric Critical Care and Surgery in Children Operational Delivery Network Director, East of England
Dr Shil Patel, Paediatric Intensive Care Medicine Grid Trainee, Queen's Medical Centre, Nottingham University Hospitals
Rachel Pountney, Principal Dietitian – Neonates and Paediatrics, Bradford Teaching Hospitals NHS Foundation Trust
Dr Victoria Puddy, Consultant Neonatologist, University Hospital Southampton; Thames Valley & Wessex Neonatal Operational Delivery Network Clinical Lead
Saskia Scriven, Advanced Neonatal Nurse Practitioner, Liverpool Neonatal Partnership (Liverpool Woman's and Alder Hey)
Dr Sarah Seaton, Associate Professor in Perinatal and Paediatric Research, University of Leicester
Marina Sloan, Lead Speech and Language Therapist, South West Neonatal Network
Jennifer Webb, Lead Nurse for Paediatric Critical Care Evelina London & Royal Brompton Hospitals
Dr Stuart Wilkinson, Long-Term Ventilation network lead, Consultant in LTV/Respiratory medicine, Royal Manchester Children's Hospital
Parent and Carer panel – Catherine Archbold, Valerie Crooks, Sam Jeffreys, Victoria Walsh

Process of framework development

The scope and content of this document were determined by members of the working group and the Parent and Carer panel appointed for this framework development. The working group undertook a national survey of staff working in neonatal and paediatric services, including in paediatric critical care, to provide information regarding concerns about and attitudes to transition to inform the framework. In addition to written feedback and virtually meeting with the Parent and Carer panel, the working group also undertook a survey of an additional group of parents who have experienced complex transition to further develop its understanding of the process from families' perspectives.

Following the consultation process, the working group received a very large volume of feedback from both individuals and organisations, for which it is extremely grateful, and from which the framework has benefitted hugely. The group would particularly like to thank those organisations who have provided their endorsement.

Language

The British Association of Perinatal Medicine is committed to continuously fostering a diverse environment. We acknowledge the effect language can have on individuals and populations. For simplicity of language, the framework may use the terms woman and mother throughout, but this should be taken to also include people who do not identify as women, but who are pregnant, in labour and in the postnatal period. The term breastfeeding is also used but should be taken to include those who term this method of feeding as chest or body feeding. Please always take time to make sure you are using the preferred pronouns and terminology of the baby, their parents/family and their support network.

Parents and families

BAPM recognises the huge variety of people that it takes to care for and raise a child. For the purposes of this framework, 'Parents' and 'Families' include all individuals and groups who provide care, love, and support to a baby. This includes biological, adoptive, step and foster parents, guardians, grandparents, extended family members, or chosen family members who have a nurturing role in the baby's life.

Key recommendations

Team working

1. Neonatal and paediatric services should work together to enable babies to transition into paediatric services when it is appropriate for their clinical condition, postnatal age, size and developmental stage. Care should be provided in the right place at the right time, and as close to home as possible.
2. All services should understand this shared responsibility and work together to promote the continuum of care based on individualised healthcare needs.
3. A multidisciplinary team approach, with collaborative input from medical, nursing, allied health professionals, psychology & pharmacy (AHPPP) and other support staff across clinical services is essential.

Coordination and delivery of care

4. There should be a named responsible consultant for all clinical teams involved (e.g., neonatology, general paediatrics, respiratory, critical care, paediatric surgery, palliative care), they should maintain a longitudinal overview of the baby's care and mitigate loss of key information during transition.
5. A named 'lead' responsible consultant and team caring for the baby should be responsible for coordinating healthcare wherever the baby is located. The consultant and team that is identified with this role will depend on the baby's clinical needs.
6. Each Trust/Health Board should have a process that supports the coordination of transition, including identification of a staff member responsible for each baby's transition journey, who can be a single point of contact for the parents.
7. There should be clear timelines set locally for subspecialty involvement relevant to the baby's needs. There should be three-way multidisciplinary planning meetings before and after transfer, involving families, neonatal services and involved paediatric services.

Families

8. Parents must be recognised as partners in their baby's care and decision-making, regardless of their baby's location, reflecting their expertise in their baby's care. Where parents have been supported to assist in aspects of care, this should be recognised in documentation that moves between care settings.
9. Families should be cared for using a culturally sensitive, trauma-informed and family centred approach. The family-integrated care (FICare) philosophy is hugely appreciated by families, has a strong evidence-base for improved outcomes in neonatal care and should be further developed within all paediatric services.
10. Services should actively identify, record and address barriers that may limit parents' ability to actively contribute to their baby's care. This includes recognising social, economic, cultural, and practical challenges and taking steps to mitigate these.

Communication

11. Robust handover of information is essential, including verbal handover at a senior level between teams. Comprehensive standardised transition documentation should be used to ensure crucial short-, medium- and long-term plans and discussions are understood and documented. This should include handover of medical, nursing and AHPPPs' plans of care and relevant information relating to conversations with the family.

12. There should be respectful communication between teams, with an understanding of the challenges, skills and approaches of clinical teams caring for babies at all stages of their postnatal journey. Parents must be kept informed of the baby's progress and each team's clinical plans.

Support and oversight

13. Trusts, Neonatal and Paediatric Operational Delivery Networks (ODNs) and Health Boards should support collaboration between specialities and services to develop a shared understanding of their cultural and practical differences in care. This should promote development of pathways of care, governance and review processes including audit standards to support effective, equitable transition for babies moving within and between hospitals, across regions and network boundaries. These processes of leadership and oversight must include parent representation and ensure there is a focus on improving the family experience.

14. Workforce skills should meet the baby's requirements wherever care is provided. There should be appropriate education and training to ensure staff have the competencies and confidence to care for more mature babies and babies with complex healthcare needs and their families on neonatal and paediatric critical care and paediatric wards. Trusts, ODNs and Health Boards should consider developing joint working and/or training opportunities with neonatal, paediatric and paediatric critical care teams to achieve this.

15. There should be local and regional review of staffing capacity and demand to support transition, in particular nursing and AHPPP services to ensure compliance with national standards, equity of services and continuity of care.

Introduction

More babies survive after neonatal intensive care following preterm births and other serious medical conditions than previously, leading to increasing numbers of children living with lifelong healthcare needs (1-3). They may need ongoing care from community paediatric services, specialist outpatients, children's wards, high dependency (level 2) and paediatric intensive care units (PICU).

Compared to children born at term, children born extremely preterm (<28 weeks' gestation) have approximately five times the rate of hospitalisation throughout childhood (4). Children with lifelong clinical conditions face repeated hospital stays in early life; this may include PICU admission when critically ill (5). Approximately half the children under two years of age admitted to PICUs have experienced neonatal critical care; a third of them are admitted to PICU more than once. These babies represent a very small proportion of all neonates, with approximately 5% of babies who have been admitted to neonatal units subsequently admitted to PICUs (6). Babies who transition as inpatients to paediatrics make up less than 5% of neonatal admissions, with <1% transitioning directly to PICUs (7). However, these babies often have medically complex conditions, e.g., long-term ventilation (LTV), longer term enteral tube feeding, and require extended and ongoing inpatient and outpatient care, and may have a very guarded prognosis.

The most medically complex babies being discharged from neonatal units will benefit from a transition pathway from NICUs to paediatric services. Up to 20-25% neonatal and paediatric colleagues are reported to have access to local or regional guidance on neonatal to paediatric transition (data from a survey conducted by the working group); however, data on the experience of transition and the use of transition pathways are sparse.

Transition is wider than the transfer of clinical care; it is a relational and emotional experience for families and healthcare professionals, and it may be difficult to navigate (8). Continuity of high-quality holistic care depends on effective communication of clinical and other relevant information between teams using a family integrated care model with shared decision making throughout (9,10).

Structural and cultural differences between services may challenge seamless transfer of care to the detriment of families' and health care professionals' experience (11). Transition may involve ethical dilemmas, and conflict may arise between healthcare teams or with families regarding healthcare priorities and expectations, especially when the prognosis is uncertain (12-15).

This framework for practice aims to describe principles for safe, effective and personalised transition of care of babies from neonatal to paediatric services; this includes holistic support of their complex health and care needs and their families' psychosocial welfare. It also provides information to services and regional bodies on what is required to further develop high quality transition pathways.

The framework includes:

1. Inpatient transition to specialist paediatric services.
2. Inpatient transition to secondary paediatric services.
3. Transition to specialist outpatient paediatric services of babies with long term healthcare needs/ medical complexity.

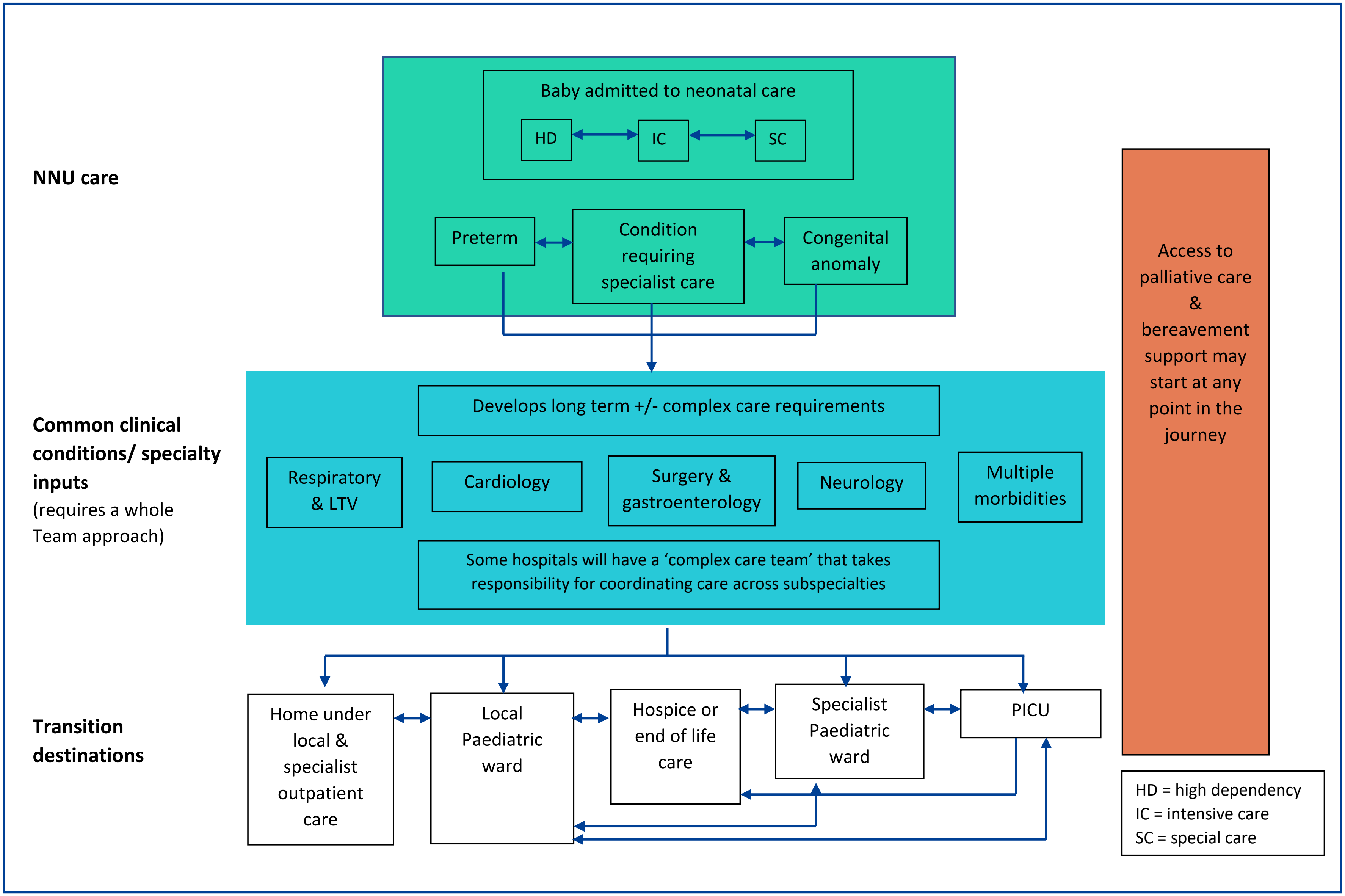
It does not include routine neonatal discharge pathways, regular outpatient care, health care involving a single subspecialty, or end of life pathways.

Glossary

ACP	Advance care plan
AHP	Allied Health Professional
AHPPP	Allied Health Professional, Pharmacist & Psychologist
BAPM	British Association of Perinatal Medicine
CGA	Corrected gestational age
CLD	Chronic lung disease
CNS	Clinical Nurse Specialist
CPAP	Continuous Positive Airway Pressure
DT	Dietitian
ENT	Ear Nose & Throat
EPR	Electronic patient record
FICare	Family Integrated Care
HD	High dependency
HDU	High Dependency Care Unit
HIE	Hypoxic ischaemic encephalopathy
IC	Intensive care
IVH	Intraventricular haemorrhage
LGBTQ+	Lesbian, gay, bisexual, transgender, queer (and more)
LLC	Life-limiting conditions
LNU	Local Neonatal Unit
LTV	Long-term ventilation
MDT	Multidisciplinary Team
NEC	Necrotising enterocolitis
NHSE	National Health Service England
NICU	Neonatal Intensive Care Unit
NIV	Non-invasive ventilation
NNU	Neonatal Unit
ODN	Operational Delivery Network
OT	Occupational Therapy/Therapist
PCC	Paediatric Critical Care
PPC	Paediatric Palliative Care
PICU	Paediatric Intensive Care Unit
PMA	Post-menstrual age
PN	Parenteral nutrition
PT	Physiotherapy/therapist
PCC	Paediatric Critical Care
PPC	Paediatric Palliative Care
RCPCH	Royal College of Paediatrics and Child Health
RSV	Respiratory Syncytial Virus
SLT	Speech and Language Therapy/Therapist
SC	Special Care
SCU	Special Care Unit
TEA	Term equivalent age
TiC	Trauma-informed care
TOF/OA	Tracheo-oesophageal fistula / oesophaegeal atresia

Pathways from neonatal care

Figure 1: Pathways from neonatal care



Most babies are discharged home from neonatal care with standard primary care, community care, neonatal outreach and neonatal routine outpatient follow-up and/or high-risk neurodevelopmental surveillance where needed.

A proportion of babies with ongoing complex healthcare needs require medium or long-term healthcare. As they mature, their inpatient needs are more suited to paediatric than neonatal services. After discharge from hospital, they are at high risk of readmission and require organisation and oversight of specific care needs. These babies require multidisciplinary input from a team or teams of medical, nursing and AHPPP professionals.

Where transition is not to general paediatric services, care will generally be handed over to a lead subspecialty aligned to the baby's most significant clinical condition. Other subspecialty MDTs are included in the transition process for babies with health care needs that overlap with subspecialties. Refer to Multidisciplinary teams section. Appendix 1 provides detail on some of the medical and surgical conditions in newborns that will need to transition and MDT involvement.

Preterm babies at or after term equivalent age (TEA)

Ex-preterm babies are a significant proportion of babies that transition to paediatric services. Survival after birth at the extremes of gestation is increasing, these babies are more likely to have chronic illnesses (1-7).

Perceptions about outcomes and the scale of the ongoing healthcare needs of ex-preterm survivors often vary between neonatal and paediatric healthcare professionals, leading to differences in opinions about care and the best pathways for these babies (see MDT section).

Families will have spent a long time in NNUs and have a high degree of familiarity with their baby, care and communication practices. The differences they notice in the approach between neonatal and paediatric teams makes the experience of transition challenging for families and health care professionals. See Family Support section.

The transition process is influenced by the number and complexity of a baby's healthcare needs. Children with medical complexity need robust transition planning; their care may be coordinated by a specific specialty team, referred to in this document as the 'Children with medical complexity team'.

Children with life-limiting conditions (e.g., complex neurodisability, genetic syndromes, such as trisomy 13 and 18) may require care well into infancy and beyond. Particularly careful consideration of the prognosis and paediatric palliative care involvement is beneficial in decision-making which may require ethics and 'best interests' discussions, and development of agreed advance care plans.

Transition destinations

Babies may transition to various locations (Figure 1) within the same hospital, between hospitals and across regional neonatal and paediatric network boundaries.

General paediatrics

This pathway is for babies who have grown and developed to a point where their needs are better met in a paediatric environment. They will often need repatriation to their local hospitals. They require ongoing low dependency, or in some cases high dependency, inpatient care.

Critical Care

Transition to paediatric critical care is required for babies whose needs exceed care available on children's wards, e.g., invasive mechanical ventilation or non-invasive respiratory support with clinical instability. Criteria differ between hospitals and regions, depending on the logistics of intensive and high-dependency care services and the level of care provided on general or specialist (e.g., respiratory) children's wards. Critical care capacity can be impacted by barriers to onward transfer to lower dependency wards, including the availability of LTV beds.

Specialist Paediatric ward

Babies requiring ongoing subspecialist inpatient care with organ-specific conditions will usually transition to the appropriate subspecialty ward. In situations where it is not clear which subspecialty ward is best placed to care for a baby with complex medical needs, this should be agreed at an MDT meeting (see Process section).

Home

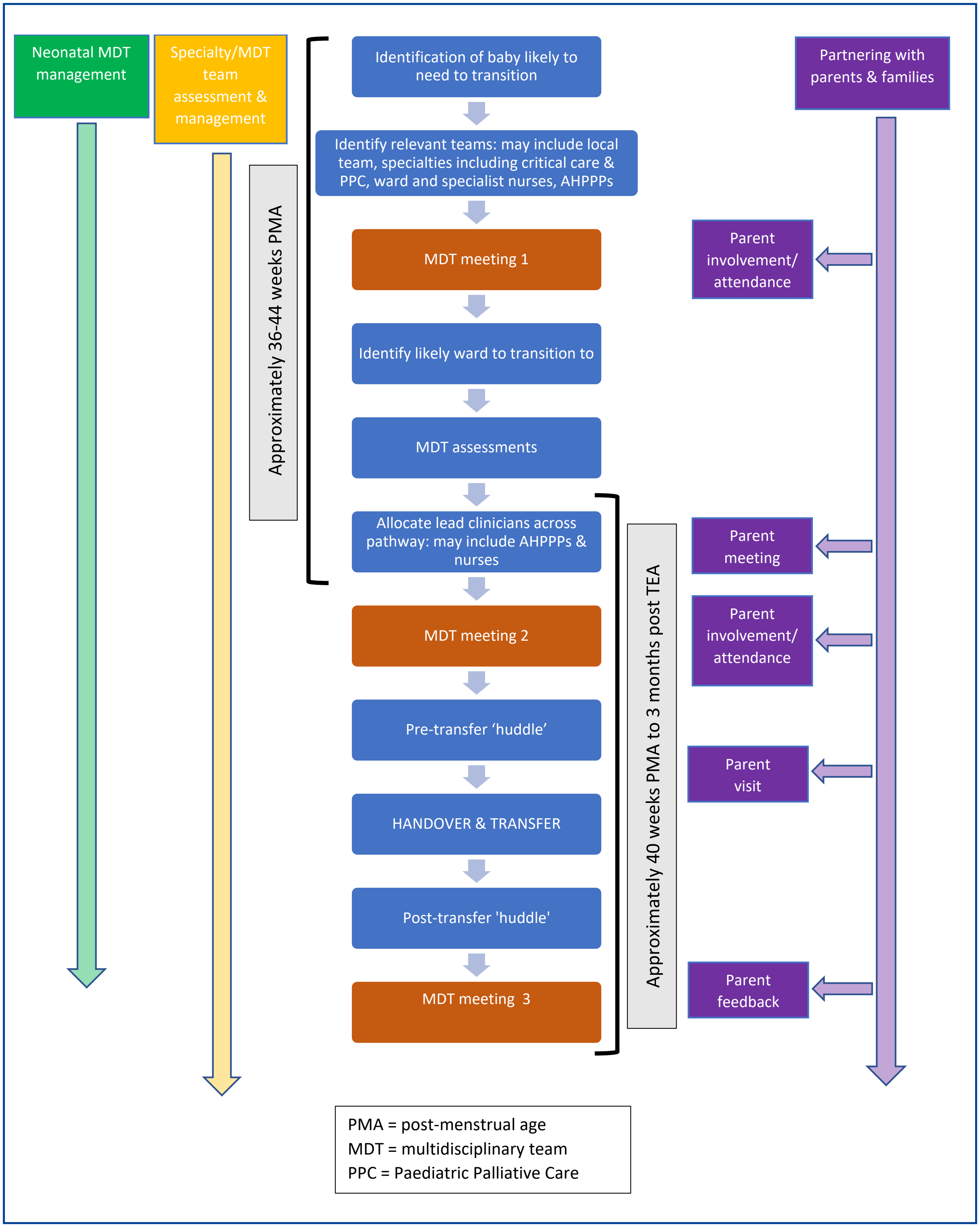
Babies going home with significant ongoing healthcare needs will require ongoing subspecialist outpatient input and have a high likelihood of readmission, either to the local or specialist hospital. Specialist teams are likely to be required to facilitate safe discharge home.

Hospice and end of life care

For babies who are considered to have potentially life-limiting conditions, transition should include assessment of the need for palliative care team involvement and may include planning for end-of-life care. This may lead to transition to hospice care, although palliative care, including end of life care, may occur in any setting. Refer to 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine, a BAPM Framework for Practice' (13).

Process of transition

Figure 2. Process of transition



PMA = post-menstrual age
MDT = multidisciplinary team
PPC = Paediatric Palliative Care

Timing

The national Neonatal Critical Care Service Specification (2024) states that neonatal services are ‘for babies who are generally (but not exclusively) less than 44 weeks corrected gestational age (less than 28 days old, corrected for gestational age assuming 40 weeks defined as term)’ (16).

The aim should be for transition from neonatal to paediatric services by 44 weeks' gestation, in line with the neonatal service specification. This is supported by a recent UK staff survey of neonatal, paediatric and paediatric critical care staff (unpublished data). It is recognised that this timeline is not appropriate for all babies and for all conditions, and flexibility will need to be considered in many situations (see below). Nonetheless, arbitrary barriers to timely transition must be avoided.

Anecdotally, there is a wide variation in the age of transition across the country; establishing transition pathways to support timely transition will support babies receiving appropriate care for their gestational and developmental age in the right location.

Considerations that may lead to babies remaining on NNUs beyond 44 weeks PMA

- **Weight and size**
  Babies with some medical conditions may be small for their gestational age or have postnatal growth faltering. Weight criteria may apply to readiness for surgery (e.g., cardiac bypass), and to admission to children‘s wards, including children’s critical care.

- **Physiological stability**
  Babies may have care needs (e.g., the ability to maintain their temperature) that preclude them from being cared for in non-neonatal settings.

- **Equipment**
  Many babies on NNUs at term age have ongoing respiratory support requirements. Babies on non-invasive support, in particular, may be using equipment unavailable on children’s critical care wards and may not be large enough to transition to portable ventilators. Conversely, some NNUs may be unable to provide bilevel non-invasive support where needed.

- **Safety**
  Caution should be exercised when babies with chronic lung disease are transferred to children’s wards during winter due to the risk of exposure to viral respiratory illnesses. Consider RSV immunisation prior to transition.

- **Access to appropriate transition facilities**
  Many NNUs are in hospitals without specialist children’s wards or paediatric critical care facilities, necessitating transition to other hospitals bringing additional challenges, e.g., less well-established clinical relationships and the need for specialised transport.

- **Capacity constraints and conflicting priorities**
  Capacity constraints and divergence in care priorities and philosophies between PICUs and NNUs may influence the acceptance of babies to paediatric critical care wards.

- **Availability of specialist services**
  The need for specialist medical, nursing and AHPPP input that may not be accessible in some paediatric ward settings (e.g., specialist tracheostomy care, stoma care, access to parenteral nutrition or specialist medicines, and appropriate resources for AHPPP support).

Considerations that may encourage transition into paediatric services in line with service specifications

- Well established specific pathways, e.g., cardiac critical care and/or subspecialty wards for cardiac surgery.
- Specific specialist multidisciplinary facilities in children's hospitals, e.g., LTV units under the care of specialist respiratory teams.
- Facilitation of investigations and/or highly specialised clinical care that are more easily achieved in paediatric settings e.g., subspecialist renal services with renal replacement therapies.
- Availability of specialist funded MDT services with specialist AHPPPs to support specific specialised care, e.g., metabolic services.
- Provision of size-appropriate care: paediatric services may have equipment and skills better suited to their size and weight.
- Provision of age-appropriate input: paediatric services may be better able to meet their neurodevelopmental needs with access to specialist AHPPPs and play therapists.
- Alignment of communication and care philosophies across neonatal and paediatric care in an organisation or network, including the provision of family-centred or family-integrated care.

Preparation

Timely prediction of the need for transition and proactive planning by neonatal teams is important to facilitate early involvement of appropriate subspecialist teams and conversations with families.

The process of transition may start at different times depending on the underlying clinical conditions. Neonatal teams should consider initiating transition planning and highlighting babies to the wider MDT if they have been born <27 weeks' gestation, are on NNU at 40 weeks CGA and discharge home by 44 weeks is not considered to be feasible.

Informing and involving teams

Also refer to Multidisciplinary Teams section and Appendix 1.

The neonatal team should identify relevant services and healthcare professionals required as per the baby's clinical needs.

- Subspecialty teams may already be involved in the baby's day-to-day care (e.g., cardiology, surgery) or should be invited into the baby's care team as the need for their expertise develops (e.g., respiratory, gastroenterology).
- It is essential to involve and refer to the general paediatric team from the baby's local hospital early. Repatriation of babies to local inpatient general paediatric services requires a similar attention to coordination and communication as for babies transitioning to critical care or specialty wards.
- Critical care teams will need to be involved in transition discussions for babies requiring or likely to require high dependency or intensive care.
- The 'Children with medical complexity team', where available within the service, can provide oversight and coordination of care for babies with multi-system involvement. Where they are not, services should consider which team will provide a holistic clinical overview for the baby. This may include the general paediatric service.
- Referral to and involvement of the palliative care team for parallel planning will be appropriate for some babies. Teams should refer to relevant ethical frameworks and seek support where

necessary to work through differing perspectives ensuring 'best interests' guide clinical decisions (12,13).

- Community children's multidisciplinary services, who will be supporting babies and families who transition to home, should be included in information sharing prior to discharge.
- Paediatric services may become involved well before transition, particularly when transition is complex or is delayed. Regular MDT discussions with these teams can significantly enhance clinical care and support eventual transfer.

> "Helpful to have an MDT beforehand (usually via teams) to discuss prognosis etc and ensure that everyone is on the same page. Really important for someone from PICU to meet the parents and ideally for parents to have a tour of PICU. Explanation and anticipation of the cultural differences between the departments reduces the stress of moving for the family." **NICU staff member**
>
> "Best cases involve timely discussion and planning prior to transfer. Allowing sufficient time for transfer to be discussed between teams, and within teams, to ensure clear communication and agreement on next steps." **PICU staff member**

Involving and preparing the family

Also refer to Family support and Transfer of information sections.

Any transition can be hugely challenging for families, particularly if they have been cared for in the neonatal unit for an extended period.

- Preparing families for transition requires an explanation about why transition is being planned. Where long term prognosis is known to be guarded, planning for transition is an opportunity to ensure parents are aware of the uncertainty, complexity and difficulty of the road ahead for them and their baby.
- Parents appreciate open, sensitive discussions about similarities and differences between neonatal and paediatric care and what this means for the care of their baby and themselves. The timing of such discussions requires clinical judgement.
- Parents should be given the opportunity to visit the receiving unit/ward to understand practicalities and meet the healthcare team. Support for parents may be required to facilitate this if travel to a different hospital is required. Families may appreciate an extended time orientating themselves to the new ward. Contact details should be provided.
- Medical and nursing staff from the receiving paediatric service should visit the family on NICU if they are not already involved in the multidisciplinary care (e.g., Critical Care team, Children with medical complexity team) if feasible. Consider introductions before the baby is transferred if AHPPP teams differ between neonatal and paediatric services.
- Personalised documentation for the baby and family (the 'Infant Passport') should be co-produced with the parents and commenced early in the process of gathering information.
- A written record of parents' activities in aspects of the baby's care (e.g., stoma care, tube feeding, giving medications) provides assurance and supports family integrated care in the receiving service.
- Where possible offer continuity of relationships for families. The coordinating member of neonatal staff can help ensure parents feel supported during transition by arranging to maintain short-term contact post-transition.
- Family Support Workers, where available, may provide practical help, emotional support, advocacy, parent education and support developmental care and bonding.

Multidisciplinary team meetings

Also refer to Multidisciplinary Teams and Transfer of information sections.

MDT meetings are a mainstay of communication for planning and executing transition.

- Effective organisation of MDT meetings is essential. It is recommended that larger services have a named person who is responsible for collaborating with the neonatal and paediatric MDT members and coordinating meetings ('transition coordinator').
- There should be a minimum of one meeting held, although in many situations there will be a need for one or more further planning or confirmatory meetings. This will be dependent on the teams involved and the complexity of the baby's needs.
- A follow-up meeting is recommended after transfer to ensure the receiving teams and the family have all appropriate information, clarify any outstanding concerns, and share learning from the transition process.
- MDT meetings should generally follow a standardised agenda. See Appendix 2.
- Parent/carer involvement in MDT meetings is essential
    - Discuss the purpose of the meeting with the family, and who it will be helpful for them to have at the meeting(s).
    - Encourage them to write down questions and support them to introduce their baby to the clinicians at the meeting.
    - Avoid medical jargon where possible, and if used ensure that this is explained in plain language at the time. Interpreters should be provided when indicated.
    - Ensure parents are empowered to ask questions.
    - Provide a written summary in plain language of the discussions, next steps, contact people, and where to find support.
- Teams may decide to have a professionals' meeting without the parent present for initial clinical discussions about the baby's plans of care. These discussions should be fed back directly to families either by including them in the meeting after these discussions have taken place, or at a separate meeting. Parents should be invited to be present at a least one MDT with the neonatal and receiving teams prior to transfer and in any post-transfer meeting.
- The attendance of all relevant MDT members should be supported by arranging hybrid in-person and virtual meetings if needed.
- A chair should be agreed; attendance documented, minutes and actions recorded and shared. These must also be available and easily accessed within the baby's clinical records in the neonatal and receiving paediatric services.
- Specialist AHPs' presence, including physiotherapist, SLT, dietitian and OT, is important to ensure the baby's wider developmental needs are understood.
- Invite specialist pharmacists from neonatal and paediatric services when the baby requires specialist medicines, parenteral nutrition or has a complex medication regime.
- Involve specialist nursing staff who provide clinical and discharge planning support, for example, tracheostomy, home ventilation or stoma clinical nurse specialists.
- Where parents have accessed or it is anticipated that they may access psychological support, the presence of the psychological professional(s) is important.
- Include the specialist neonatal/paediatric transport team that will undertake the transfer at the confirmatory MDT meeting if the baby needs specialist care during transfer (e.g., respiratory support, complex intravenous infusions).

Transfer and immediate approach post-transition

- There will often be a time lag between the confirmatory MDT and the transfer. In these circumstances, an update meeting, or 'huddle', should be held in the days immediately pre-transfer to confirm the baby's current clinical status and discuss any parent or healthcare team concerns.
- Inter-hospital transfer should be undertaken by a specialist neonatal or paediatric critical care transport team if specialist care is required during transfer, depending on regional practice and availability.
- Transfers should generally happen in daylight hours and not at weekends; it is best practice for transfers to be earlier in the week to facilitate access to the relevant professionals during the working week.
- Recognise that the process of transfer is intensely stressful for families.
- Ensure all relevant clinical information, including medical imaging, is available to the receiving team. Receiving teams should also have access to the relevant Infant Passport and any documentation of activities parents are able to do as part of their baby's care (see Transfer of information section).
- All teams involved in care before and after transition play a role in ensuring continuity of clinical management plans. This will need communication between referring and receiving teams beyond the transfer event to minimise loss of information.
- Ongoing engagement and support from neonatal teams needs to be considered in the immediate period following transfer. A post-transfer 'huddle' can be useful to resolve any immediate concerns or questions. Input from neonatal teams to support general paediatric teams in management of any ongoing neonatal-related issues can be helpful.
- A post-transition MDT meeting is likely to be best organised within a few weeks of transfer. Ensure the family's voice is heard in this meeting.

Acute or unplanned transfer

- On occasion it may be necessary to transfer babies to paediatric services without the opportunity for forward planning. Some circumstances where this might be required are:
    - Where urgent specialist care is needed
    - To create neonatal unit critical care capacity
- It is essential to ensure that comprehensive handover of all elements of care occurs.
- Parents should be informed early, given a clear explanation of the rationale, and the logistics of the transfer.
- The same principles of sharing information and parent support post-transfer apply.

Longer term aspects post-transition

- Many of these babies have very prolonged stays in hospital; teams should ensure that important aspects of neonatal longer-term follow-up (e.g., neurodevelopmental surveillance) are provided.
- For families discharged home with neonatal or paediatric outpatient follow up, neonatal teams should consider having conversations with families about the possibility of future admission(s) to hospital. It may be helpful to build an awareness in a similar way to preparing families transitioning directly to children's inpatient services.
- Additional important considerations:
    - Community children's services provide multidisciplinary support for babies with complex care needs, including extremely prematurely born babies.

  - Universal services (e.g., General Practitioners and Health Visitors) form a crucial part of the team around the child.
  - Families may need referral to social care support or safeguarding teams.
  - Babies with ongoing complex care needs will often require assessment to inform home care package provision.
  - Housing, home environment and access, especially if a child has significant technology dependence or home requirements.
  - Hospices play a role in providing additional support for babies in the community, including respite care.

Monitoring and improving transition

- Neonatal and paediatric services within hospitals and regions should collaborate to improve transition pathways and remove barriers to effective transition.
- Consider facilitated reflective practice for involved clinicians to learn from the transition experience for particularly complex clinical situations, alongside reviewing feedback from families and regular peer review meetings.
- An ongoing clinical audit and/or quality improvement approach applied to guidelines, pathways, multidisciplinary team education and training resources, and parent information resources is the foundation for developing safe and effective high-quality holistic transition.

Multidisciplinary teams

Who makes up a team?

The term ‘team’, when used in this document, always refers to all professionals that provide input into a baby’s care, with the assumption that the expertise brought by everyone is indispensable. This includes doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, dietitians, infant feeding specialists, pharmacists, psychologists, play therapists and all other support staff, regardless of grade.

National documents are available that give guidance for the workforce and skills that these staff bring to neonatal and paediatric care. There are explicit workforce standards available for medical and nursing staff in neonatal and children's inpatient care units, including critical care (17-20); and for AHPPP staffing for neonatal critical care (21-26). The AHPPP workforce is central to providing ongoing care for complex infants in paediatric environments and clearer recommendations would benefit the development of high standard services.

It is the responsibility of services to assess the staffing required across the whole MDT to provide care for babies needing to undergo transition from neonatal care. Where services are not compliant with national workforce recommendations or require uplift of staffing in line with their activity, Trusts, Health Boards and Networks need to work together to ensure adequate funding and workforce planning to achieve this.

Whole team approach: whose patient?

Many families report their experience of transition is disjointed and communication between care professionals is confused and contradictory. This is also the experience of clinical teams, where care goals are not aligned; conflicts can interfere with the transition process. **For babies who transition into paediatric care, constructing a joint team approach, with shared responsibility and aligned care goals, is crucial.**

Leadership and coordination of transition and ongoing care

Responsible consultants

Babies with prolonged NNU stays and those with complex or multi-system clinical conditions should have a named responsible consultant neonatologist to provide continuity of care. They play a key role in transition, coordinating the liaison between different medical paediatric and subspecialist teams and being the key medical point of contact for the parents.

Similarly, for babies who have ongoing subspecialty input on NICU, there should be named responsible subspecialty consultants. For surgical babies, this is likely to be the consultant surgeon who has operated on them. Allocations for other services, e.g., cardiology or respiratory, where many consultants may have provided care over time, may be less obvious, but should nonetheless be explicit. This helps to maintain consistency, continuity of care, and mitigates loss of information during the transition process.

Once decisions are made regarding transition to paediatric services, responsible consultant(s) should be allocated to the baby from the receiving teams. Where additional teams become involved, or the baby is transferred to a different hospital, these allocations should be clear ahead of transfer where possible.

Parents should be made aware of their baby's responsible consultants from all specialties and given the opportunity for regular communication with them, particularly when transfer of care is approaching. Services may also consider allocating a named person to lead on non-medical aspects of a baby undergoing transition. This may be a link nurse or AHP, considering the baby's wider needs.

Managing coordination of transition

Coordination of transition is complex and is best achieved when the responsibility for organisation is explicitly allocated. Models for organisation of transfer or discharge vary between hospitals. Assigning a designated lead or point of contact, such as a 'key worker', transition coordinator or discharge planning or outreach coordinator should ensure seamless communication between teams during transition (16, 17, 27). Families should have access to their 'key worker' during transition and after transfer of care until matters identified post transition have been resolved. Children with medical complexity or discharge planning teams have skills and contacts to facilitate transition with a family-centred approach.

Teams and teamworking

Refer also to Pathways and Process sections.

Appendix 1 provides a summary of multidisciplinary team involvement and coordination.

The recognition that transition can be challenging for parents and clinicians has driven the development of this framework. A survey of neonatal and paediatric multidisciplinary staff nationally revealed some common anxieties relating to communication and perceptions that may affect clinical relationships during transition (185 responses, unpublished data):

- The impact differing perspectives on prognosis have on clinical decision-making.
- Perceived reluctance to discuss end of life care or involve palliative care.
- Giving information to parents about severity of illness related prognosis.
- Differing approaches to supporting parents and involving them in day-to-day care.
- Reluctance to accept babies for transfer.
- Lack of respect between teams regarding approaches to care and decision-making.
- The undervaluing of some patient groups.

Open communication and constructive relationships between neonatal and paediatric teams are very important to ensure transition is achieved effectively for babies and families.

Trusts and Health Boards should consider developing joint working and/or training opportunities with neonatal, paediatric and critical care teams to ensure a shared understanding of neonatal care and ongoing care needs for babies following transition. Attention should also be given to staff wellbeing in this challenging area.

> "There is such a big cultural difference between NICU and PCCU and I don't feel the families are always adequately prepared for this. We have had some extremely challenging long-term families in the last couple of years and I genuinely think the team feel anxiety at the prospect of neonatal transitions, which I have no doubt is obvious to families." **PICU staff member**
>
> "I have often noted that PICU teams can perceive a patient to be generally challenging because they have not been well managed on NICU which is unfair and simply serves to break the opportunities to support each other. These patients are complex. I believe NICU has increasingly complex babies due to increased survival rates of lower gestation babies which PICU doesn't seem to be supportive with at times. In reality NICUs manage a huge number of babies well and only a tiny proportion go to PICU for ongoing care." **NICU staff member**

Family support

Understanding the parents' perspective

When a baby transitions from neonatal to paediatric care, healthcare teams must consider the parents' emotional and practical needs from *their perspective:* their baby continues to be vulnerable; they face continuing uncertainty and adjustment to the longevity of their baby's healthcare needs. Along with the baby's move, parents are transitioning into the next phase of parenthood and may feel a mixture of relief, excitement, happiness, fear, anxiety and loss as transition approaches. In addition, there are practical considerations for families, e.g., provision of accommodation, fear and anxiety relating to the physical transfer and the unknowns of the new environment. Multiple pregnancies add an extra dimension of challenge for families, particularly when separation of multiples may be enforced by transition.

Appreciating the context of their parenting experiences

By the time of transition, parents bring unique expertise to their baby's care, they provide continuity and are aware of their baby's holistic needs. Healthcare professionals should embrace the families' significant knowledge, skills and contributions, and actively elicit their opinions and concerns as equitable partners. This includes, but is not limited to, being able to provide care (e.g., feeding, including enteral tube feeding) and knowing how best to comfort and soothe their baby.

Families facing barriers such as work commitments, caring responsibilities, travel costs, or lack of stable housing may struggle to participate fully in their baby's care, leading to inequitable experiences and outcomes.

Identifying and meeting psychosocial needs

Good psychosocial support is about being alongside families; noticing and containing emotions, being curious, empowering, gently normalising the complexity families are carrying, and putting support in place as appropriate. It is important that during transition, all team members are sensitive to each family's unique needs, values, and preferences.

- Provide interpreters and culturally appropriate resources.
- Ask about spiritual or cultural practices that matter to the family.
- Offer trauma-informed care with an awareness of adverse life experiences and the impact of discrimination and marginalisation in the context of transition (see box below).
- Recognise and take account of the higher prevalence of common mental health difficulties in parents whose child has been in neonatal care compared to the general population.
- Consider how to meet the needs of diverse family structures, including LGBTQ+ and those with disabilities; inclusion of peer support networks may be beneficial.
- Consider how to meet specific needs (e.g., literacy, cognitive impairment, neurodiversity).
- Consider if families have any wider social needs (e.g., housing, education, employment, finance) and seek to help them to overcome these.
- Where transition separates babies from multiple pregnancies, consider how families can be supported to mitigate the impact, including considering practical help e.g., travel.
- Consider the needs of siblings as appropriate to their age and development. Local authorities ('early help'), health visiting services and voluntary and charitable organisations may be helpful.
- Actively seek to understand and incorporate strengths and protective factors that families can draw on (e.g., spiritual practices, friends and family, confidence in approaching healthcare staff).

Some methods to support adjustment are:

- **Mark milestones:** Units may hold "graduation" celebrations to mark how far the baby and family have come; and use mementos that can be continued in a new environment.
- **Creating rituals:** Establish a simple evening ritual that parents can continue when they begin staying overnight on the children's ward.
- **Assigning a 'transition buddy':** refer to Managing coordination of transition.
- **Including touches of familiarity in a new environment:** Learn about a family's routine and facilitate this continuing as much as possible.

Trauma-informed care (TiC)

Transition can be an overwhelming experience, especially given direct or indirect traumatic experiences during pregnancy and the perinatal period, and in the context of pre-existing vulnerabilities and adverse life experiences (28). TiC during transition promotes understanding the effects of psychological trauma and the continuing impact of these on how parents cope cognitively, emotionally and behaviourally with their baby's move between services.

Trauma-informed care (29):

i. Realises what has happened to people
ii. Recognises the impact of these experiences and common trauma responses
iii. Responds to peoples' distress and reactions to overwhelmingly frightening experiences
iv. Resists/mitigates further trauma where possible, by ensuing families feel safe, heard, valued and respected.

Parents suffering from ongoing trauma responses should be offered continuity of relationships wherever possible and there should be steps taken to minimise re-traumatisation. During transition, parents may benefit from a shared agreement about what would be helpful for wider team members to know, and how to make them aware of previous traumatic experiences (e.g., birth trauma, witnessing resuscitation, being told their baby might die), so they do not have to repeatedly relive these experiences in further conversations.

Additional information about and evidence for trauma informed approaches in neonatal care and the perinatal period can be found in Sanders and Hall (30), and in the NHSE good practice guide (31).

Navigating clinical and cultural differences within neonatal and paediatric settings

It is important to prepare families for differences in neonatal and paediatric services, and across hospitals and regions to equip them to navigate and adapt to the many clinical, practical and cultural differences between settings. These differences may include changes in the environment, methods of monitoring, clinical focus, team structure and practices relating to language, communication, parental presence and accommodation, and assumptions about care.

While all services aim for child wellbeing and parent partnership in care, they can operate with different philosophies, routines, and expectations, which can feel challenging to families transitioning between them. Parents have described feelings of disempowerment, frustration and dissatisfaction in transition from neonatal to paediatric environments. Many parents express a desire to be present on ward rounds, involved in discussions and decisions around care for their babies and being able to engage safely in the aspects of provision of care (e.g., administering medicines) where their baby's condition allows. These aspects of family involvement are central to the family integrated care model.

Often there are practical differences between healthcare settings which are unclear to families (e.g., why a baby has moved from an incubator in the neonatal unit to an open cot in the paediatric setting). Staff should be mindful of these differences and work with families to explain the reasons for the way clinical care is provided.

Different language or phrases used across settings which may relate to similar or identical aspects of a baby's care can be confusing for parents and they may need help navigating the new language and lens through which their child is seen.

"Try and visit and get information about the ward you are going to. It can be very confusing. The staff do not always explain things i.e., how alone your child will be if you're not there."
Parent

"[Hospital] and [Hospital] were the epitome of family centred care. We were part of every discussion and our opinions were given very serious consideration. In [hospital] and [hospital] however, we were treated as a nuisance – at one point told to make a FOI* request when we asked about our daughter's CRP level during an episode of sepsis. We had to fight to be included in the rounds or even to be heard when we saw our daughter was displaying the same signs of sepsis as previously."
Parent

**Freedom of Information.*

Family Integrated Care (FICare)

Family Integrated Care (FICare) is a model of care which promotes a culture of partnership between families and staff to enhance care of babies requiring critical care after birth (32). Following recommendations from the Neonatal Critical Care Transformation Review in 2019 (33), FICare is becoming standard of care nationally within neonatal services.

BAPM describe five key principles of FICare:

i. Families are considered equal partners in the care team, including in shared decision-making.
ii. Families are empowered by education and support to engage fully in their baby's care.
iii. Family mental health and welfare and staff wellbeing are prioritised.
iv. A shared and collaborative culture that promotes the integration of families into the delivery of care.
v. An environment which enables parents to spend as much time as they wish with their baby.

A strong evidence base has built up that supports FICare within neonatal units, including benefits of increased breast milk feeding, earlier discharge, reduced readmission and improved parental wellbeing (32).

"As a family we fully embraced the FICare lifestyle. We were ever present on the wards from 7am-8/9pm. We were present on all ward rounds from Day 1 and were providing all the care that we were allowed from very early on. We were also involved in nearly all conversations about the management and presented him during ward rounds as if we were a staff member. This is in great contrast to every experience I have had on a paediatric ward where the care is still dictated by the paediatric team. Often management discussions are had separately and then the parents are just informed of the plan." **Parent**

Communication with families

An empathetic, open professional relationship with personalised communication using preferred terminology (for example, using baby's name rather than "baby", and asking parents how they would like to be addressed) provides a foundation for sensitive and clear communication. Healthcare professionals should have a non-judgmental approach, avoid phrases like "difficult families", "complex children", "clinical problems" and try to understand and empathise with the families' extraordinarily difficult circumstances.

Parents need clear, honest, sensitive communication that is accessible to understand the reasons for, and the process of transition. They should be given time to process information, be listened to, and have their questions answered with compassion.

> "I think one big question to ask those transitioning from NICU to paediatric environments that would potentially help many families is 'what are your expectations of life on paediatric wards?' This question will enable the wards to work out the starting point they are working from and what prep work needs doing to meet in the middle. This will likely lead to reduction in friction between parents that are expecting NICU level care on paediatric wards where it is not possible. If the expectations can be managed and realigned early on, this would help greatly." **Parent**

Good interprofessional collaboration including the family throughout the transition process can help towards making families feel safe, supported, and confident; and promote a shared understanding and purpose between families and healthcare teams.

Talking about transition

- **Prepare the conversation**: Ensure all teams are aligned on the plan before speaking to the family.
- **Set the emotional tone**: Start by recognising the baby's progress and the family's journey so far.
- **Frame it positively and honestly**: Highlight the baby's progress while acknowledging that moving can feel scary. Balance realism with hope, avoiding false reassurance.
- **Facilitate new relationships**: Lay foundations for building positive, trusting relationships with new professionals/teams involved.
- **Normalise and validate emotions**: Tell families it is common to have mixed feelings, e.g., to feel excitement *and* anxious/sad about this next step.
- **Collaborate with each other**: coordinate consistent messages to families and avoid conflicting messages.
- **Think about preparing families longer-term**: Ensure the focus of transition conversations extend beyond the initial transfer and incorporate longer-term considerations for the family.

Transfer of information

Clinical communication

Crucial information about the baby and family may be easily lost when babies transition between clinical teams, wards, hospitals and to home, particularly when babies have been inpatients for a prolonged period and have multiple, complex medical needs. Services should develop robust processes and documentation to ensure this does not happen; using checklists may standardise practice.

The information shared should include all medical, nursing and AHPPP clinical concerns, infant feeding support and management plans. Also highlight information that is important to parents and families and record this in the Infant Passport.

The referring team is responsible for providing appropriately detailed, accurate information to the receiving team(s). Likewise, the receiving team(s) is responsible for ensuring they retain, understand, and consider the information to ensure continuity of patient care.

Serial handovers between the referring, transport, and receiving teams and different electronic clinical records systems may increase the likelihood of information loss. Teams must mitigate this and ensure comprehensive documentation, growth charts, medication and immunisation information, and relevant medical imaging and reports are transferred with the baby.

Handover

- Handover is a process, not a single event, which starts from the transition planning stage (see **Process section**).
- Senior clinicians should take responsibility for accurate handover of important information between teams. Where possible, this should be between named responsible consultants (see **MDT section**).
- Standardised handover tools help to ensure all critical information, clinical (medical and nursing, including medications), developmental, and family concerns, is shared across settings.
- A verbal, face-to-face handover at the time of transfer is extremely important, so that clinical professionals taking over care at the baby's bedside receive all important information. This may be undertaken by the transport team if the baby moves hospitals. However, this is not a substitute for detailed handovers between senior clinicians.

Discharge documentation

- A written summary of a baby's clinical course is essential for the safe transfer of care. If there is more than one relevant episode of care, one summary should have information on all episodes, or summaries of each episode should be provided. This should also be available in electronic format where possible.
- The balance of providing detailed information that is succinct and relevant is difficult. Oversight of discharge documentation by senior clinicians is advised to ensure this balance is achieved.
- Integrated electronic patient record (EPR) systems, compatible across neonatal and paediatric services, present opportunities to improve information sharing. Ensure EPRs reflect input from all professionals, minimising the risk of loss of information. Trusts and Health Boards should be mindful when developing electronic patient records to provide systems that support accurate transfer of information.
- Documentation should also include a list of relevant names and points of contact for team members from involved subspecialties and disciplines.

- Relevant medical images and reports should be shared within clinical records across hospital services.
- Discharge information should be circulated to the wider teams who will be involved in the long term, including local paediatricians, community and GP services.

Parent communication and the 'Infant Passport'

The use of a document that is co-produced with families and all involved services helps to communicate complex personal health information and build a shared understanding of a baby's and family's needs and expectations. The term 'Infant Passport' is used to describe this in this Framework document.

The infant passport should travel with the child across/between hospital settings and home. It is expected that this document will be carried by the family in the long term and will be added to over time. It is meant to complement clinical communication within handovers and discharge summaries. Currently there is not one standard document, so it is recommended there should be a passport recognised by all paediatric services at least across a region, where transfers between services are likely.

The infant passport should include at least the following information:

The baby

- All about me: Healthcare details and information about what I enjoy, dislike etc. Include a photo if my parents would like this.
- About my family: names of my parents/caregivers, siblings, people who are important to me.
- Information about what my family can do to help look after me e.g., tracheostomy care, feeding, including enteral tube feeding, giving medication; including training and assessment undertaken.
- Who are the healthcare professionals who know me?

The parent(s)/carer(s)

- Preferred names; relationship to the baby.
- What we would like the healthcare teams to know about our baby and about us.
- What is important to us and our family (e.g., spiritual/cultural/communication needs).
- What our wider support network consists of.
- Any traumatic experiences; how we would like health professionals to talk to us about these if at all, and what we might need during transition.

The passport should empower parents to advocate for their baby as they navigate their healthcare experience, and it is owned by them. In addition to this document, a parent-held clinical advance care plan document can be used to provide key information on clinical conditions, safety netting, and emergency plans related to managing complications; e.g., emergency plans for infants on long-term ventilation, or contingency plans for seizures.

Documentation of activities parents can do as part of their baby's care

A documented record of the parents' experience in providing specific aspects of care, such as stoma care, enteral tube feeding, use of medical equipment (e.g., feeding pumps, portable ventilators), can provide assurance of the parents' knowledge and skills in providing specialist care. This facilitates safe family integrated care and supports parents to provide "technical" aspects of care following transfer of care. Local services should use their governance processes to ensure safety and ensure that parents' skills are maintained.

Recommendations for future work

1. Further research is required, focusing on:
    a. Improved understanding of the numbers of babies who transition into Paediatric services, with information on neonatal, paediatric and critical care perspectives; and their longer-term outcomes.
    b. Parents' experience of babies with complex transition journeys.
2. Neonatal and Paediatric ODNs, Health Boards and commissioning organisations should assess capacity requirements, funding and commissioning of appropriate services for babies requiring transition, particularly for babies requiring ongoing critical care, technology dependence and children with medical complexity.
3. RCPCH should lead national work to examine the challenges for all services from caring for children with medical complexity that transition from neonatal care, including those born extremely preterm:
    a. Develop standards and auditable metrics to measure effective and high-quality transition and support quality improvement
    b. Seek to understand and mitigate cultural differences between health care professionals in neonatal and paediatric critical care services.
    c. Reduce barriers to transition, examples are: access to appropriate non-invasive respiratory support in babies with severe chronic lung disease; and the provision of teams who specialise in caring for children with medical complexity
4. Royal Colleges, professional bodies, ODNs and Health Boards should support improvements in staff education and professional development resources, focusing on:
    a. Development of FICare practices in non-neonatal environments.
    b. Educational resources for additional support to upskill neonatal and paediatric staff on the care of preterm, ex-preterm infants and those with medical complexity.
    c. Introducing requirements into specialty curricula for paediatricians in postgraduate training, in particular, neonatal and paediatric critical care and paediatric respiratory specialisms.
5. Royal Colleges and professional bodies should work together to develop more comprehensive MDT staffing standards for paediatric critical care and children with medical complexity, including for AHPPPs.

Appendix 1:

Transition from neonatal to paediatric services: summary of MDT involvement and coordination

This table provides a summary of key considerations for babies transitioning from neonatal units to paediatric services. It is designed to support healthcare teams in planning and coordinating care for complex and long-term needs.

Area of Need	Examples of Conditions	Reasons for Transition	Specialty Team Involvement	Transition Considerations/ Responsibilities
Neonatal Critical Care (NICU, LNU, SCU)	Critically unwell, technology dependent and preterm babies		NNU teams, includes medical & nursing staff, pharmacists, psychologists, physiotherapy, OT, SLT, dietitians, infant feeding team.	Early identification of babies likely to require transition; allocation of responsible consultant; identification of staff member coordinating transition ('key worker'); referral to appropriate (sub)specialties and health care professionals, including paediatric palliative care if condition is life-limiting. Organisation of MDT meetings. Ensure a comprehensive transfer of information. Consider support in the immediate post-transfer period. Longer term neurodevelopmental surveillance.
General Paediatric services	Need for inpatient care after term CGA e.g., CLD	Holistic oversight of all care where babies have long term health needs; repatriation to local hospitals; ongoing respiratory care; establishing feeds; discharge planning	Local Paediatric team, including medical & nursing staff, OT, physiotherapists, SLT, pharmacists, dietitians.	Involve the team from the local hospital early, including when babies transition to specialty hospitals/wards. Attend MDT meetings. Identification of responsible consultant and consider 'key worker'. Liaise with community services and primary care.
Children's Critical Care (PICU & HDU)	All sick babies from term age requiring IC or HD; preterm babies from 44 weeks PMA requiring invasive	Requirement for invasive ventilation; postoperative care (e.g. cardiac surgery); chronic lung disease with high-level NIV requirement	PICU/HDU teams, includes medical & nursing staff, physiotherapists, pharmacists, psychologists, OT, dietitians, SLT;	Early engagement in discussion regarding babies likely to transition. Identification of responsible consultant and 'key worker'. Attend MDT meetings. Meet parents prior to transition. Critical care teams should be involved in transition discussions even if the transfer of

	ventilation or high-level NIV		PPC as appropriate.	care is not planned to be to PICU/HDU, as deterioration and escalation of care may occur following transition.
Respiratory / LTV	CLD; airway anomalies; neuromuscular disorders; cardiac conditions	Babies born extremely preterm with CLD may need prolonged respiratory support. Others with congenital or acquired airway/lung anomalies or neuromuscular disorders may require LTV or tracheostomy. Transition often necessitated by reaching term CGA, need for a portable ventilator, or inability of neonatal unit to support increasing complexity. Ongoing support for feeding.	Respiratory team, includes medical & nursing staff, CNS; critical care; physiotherapists, dietitians, SLT, OT, pharmacists; psychologists. ENT team; PPC as appropriate.	Early involvement in the care of CLD, LTV planning. Identification of responsible consultant. Prepare ward/community teams for equipment, e.g., portable ventilators. Involve ENT team in case of additional airway issues or need for tracheostomy. Train neonatal staff. Liaise with physiotherapy for complex airway clearance needs – this may require assistance from critical care staff. Attend MDT meetings. Pharmacist to support RSV immunisation prior to transition/discharge. Plan for potential escalation and acute deterioration. Engage community respiratory services.
Cardiology	Congenital structural anomalies; arrhythmias; cardiac conditions in preterm infants	Transition is required for ongoing cardiac medical or surgical management. Preterm infants or those with co-morbidities may need to remain in neonatal care longer due to instability or insufficient size/maturity for intervention. Transition is delayed if cardiac surgery is postponed. Co-morbidities often necessitate wider team input.	Cardiology team, includes medical & nursing staff, CNS, psychologists; cardiac surgeons; PICU; dietitians, SLT, physiotherapists, OT, pharmacists.	Allocate responsible consultants. Engage with cardiac surgical team. Prepare for transition into PICU or cardiology ward. Consider growth-related delays. Discuss advanced care planning for complex cardiac conditions. Attend MDT meetings. Pharmacist to support RSV immunisation prior to transition/discharge.
Surgery / Gastroenterology	Necrotising enterocolitis;	Babies needing nutritional support, stoma care, or	Surgery team, includes medical &	Define lead specialty for transition. Babies who have been managed by the surgical

	short bowel syndrome; intestinal atresia; abdominal wall defects; TOF/OA	complex feeding due to short gut or anatomical anomalies. Delayed surgical interventions (e.g., TOF/OA) or complications such as intestinal failure. May need long-term parenteral nutrition.	nursing staff, CNS; gastroenterology team, includes medical & nursing staff, CNS, dietitians, pharmacists, SLT, OT, physiotherapists.	team may be handed over to gastroenterology for long term care. Allocate responsible consultant. Attend MDT meetings. Plan transfer to surgical or gastroenterology-led ward. Early dietetic input. Pharmacy involvement for PN. Involve intestinal failure team pre-transfer. Establish home PN plans if needed. Educate family. Coordinate discharge planning with community services.
Neurological	HIE; congenital encephalopathies	Need for seizure management, neurodevelopmental monitoring, complex dietary management, and therapy input. LTV often needed for neuromuscular conditions. Support for severe developmental delay and rehabilitation services required.	Neurology team; neurodisability team; respiratory team for LTV; PPC as appropriate. Includes medical & nursing staff, CNS, physiotherapists, SLT, OT, dietitians, pharmacists, psychologists.	Define lead specialty early. Plan for long-term therapy input. Attend MDT meetings. Develop individual dietary management plan. Involve pharmacy for complex medications. Include psychology and neurodisability team in transition. Refer to community AHPs. Ensure seizure plans and medication charts are up to date. Include palliative care if life-limiting condition and referral to Hospice for respite care.
Other Medical / Surgical	Airway abnormalities; neurosurgical issues; renal anomalies; genetic syndromes	Chronic conditions like renal failure needing renal replacement therapy or surgical planning. Airway anomalies requiring tracheostomy or ENT intervention. Neurosurgical issues from prematurity, e.g., hydrocephalus following intracranial bleeding.	ENT; nephrology; neurosurgery; PPC as appropriate; genetics, specialty team medical & nursing staff, CNS, OT, physiotherapists, SLT, dietitians, pharmacists, psychologists.	Prepare tracheostomy care plans. Allocate relevant specialty lead. Attend MDT meetings. Coordinate long-term follow-up and family support. Ethics and palliative care teams should be engaged early for syndromic and life-limiting cases. Create ACP before transfer if appropriate.
Babies with Complex / Multi-	Multiple anomalies;	Ongoing complex care requirements requiring long-	Children with medical complexity team (if	Require multi-specialty, coordinated care. Transition may be delayed without careful

system Needs	prematurity-related complications; syndromes (e.g., trisomy 13/18)	term inpatient care, complex discharge arrangements, and outpatient follow-up.	available); general paediatrics; specialty teams, including PPC as appropriate. Teams should include medical & nursing staff, CNS, dietitians, SLT, physiotherapists, OT, pharmacists, psychologists.	coordination – assign a lead team or Children with medical complexity service; ensure allocation of transition coordinator. Attend MDT meetings. Babies may be life-limited – early involvement of PPC, ensure MDT agreement on management goals; involve ethics team for best-interest decisions. Start discharge planning early, including community liaison and psychosocial support.
Paediatric Palliative Care	All conditions resulting in transition may be life-limiting		PPC team, including medical & nursing staff, coordinating staff, CNS, hospice services staff, OT, physiotherapists, SLT, pharmacists, psychologists.	Allocate responsible consultants. Engage in regular liaison with NNU team. Attend MDT meetings. Development of advance care plans may be necessary before transition to ensure a shared understanding of future aims. Liaise with hospices services.
Additional considerations				
Community children's services	Babies needing complex care post-discharge; preterm babies & those at risk of neuro-developmental impairment		Local team, including medical, children's community nursing team, hospice services staff, physiotherapists, OT, SLT, pharmacists, dietitians, Portage.	Neurodevelopmental surveillance, screening (e.g., vision and hearing assessments), MDT support, local sensory support service of identified hearing and/or vision needs. Ensure appropriate social services involvement. Liaise with continuing care teams.
Primary Care services	All babies		GPs, Health Visitors, other practice staff, pharmacists.	Ensure completion of immunisations. Identify support offerings in local community. Ongoing oversight of day-to-day issues. Communication from pharmacists to Primary care.

Appendix 2: MDT meeting standard agenda

1. Introduction by the chair, followed by introductions and apologies from MDT members.
2. Clarification of transition coordination and parent point of contact ('key worker').
3. Acknowledge the parents/carers' role and input. When parents are present, they should have the process of the meeting explained. Where parents are not present, it should be decided who and how feedback will be provided.
4. Invite parents to introduce their baby to the team if they would like to do so. Encourage them to share their concerns and hopes.
5. General overview of the baby's story so far provided by the neonatal team.
6. Medical input from teams involved in care.
7. Nursing input from neonatal team.
8. Input from each AHPPP involved in the baby and family's care including current treatment and long term aims.
9. Discussion of social context, requirements for parent and family support.
10. Questions invited from parents.
11. Questions invited from teams who may not yet have had detailed involvement in the baby's care e.g., critical care, palliative care, children with medical complex care team and local team.
12. Planning
    a. Immediate future care.
    b. Destination for transition.
    c. Proposed date for transfer of care.
    d. Care team(s) following transition, including those leading & coordinating care and allocation of responsible consultants (see MDT section).
    e. Process for visits to NICU of teams taking on paediatric care, visits for parents to paediatric ward.
    f. Post-transition care and review.
13. Next steps.
14. Allocation of responsibility for documentation and circulation of minutes.
15. Planning feedback to parents/carers (if not present in the meeting).

Appendix 3: Parent Information Leaflet guidance

Neonatal Unit to General Paediatrics/Specialist Paediatrics/Paediatric Critical Care

The following guidance is derived from input from parents on the BAPM Parent and Carer Panel for this framework and from a parent survey carried out by the working group (unpublished data). It can be used as a guide in creating local/regional documents to aid transition processes.

- Introduction:
    - Commence any document with positive language, acknowledging the journey that the baby and their family have been on so far
    - Acknowledge and normalise the family's likely wide variety of emotions
    - Celebrate the fact their baby is growing up e.g., their baby is "graduating" from NICU
    - Acknowledge the important role the family play in the care of their baby
- The transition itself:
    - What to expect generally (before, during, after) e.g., MDT meeting, tour of new ward/unit
    - Practicalities of a transfer including information about the transport team in the event they will be involved in the transfer
    - When transition will be (approximately)
    - The teams who may be involved
- Clearly outline the main differences between NNU and Paediatrics with the key messages of "things will be different" and "there is more than one way to do things":
    - The environment e.g., noise and activity levels
    - Equipment differences
    - Daily routines, e.g., ward rounds, bedside handovers etc
    - General care and how that might change as their baby gets older
        - For example, variation in respiratory care and feeding and reasons for this
        - Possible transition from incubator in NNU to cot in Paediatrics
    - Explanation of what is and is not possible
    - The differences in ward rounds, parent involvement and the practice of family integrated care
    - Practical parent information such as parent accommodation, access to kitchen facilities, breast feeding support and expressing spaces, food outlets available etc.
- Who the family can speak to for questions and support, with contact details where appropriate
- Consider a section for frequently asked questions (FAQs)

In summary, parent information should not be excessively detailed but should address the main parent-reported challenges of transition; realignment of expectations, transition preparation, practicalities, changes in the practice of parent involvement in care and new points of contact.

Appendix 4: Parental Transition Checklist

This is a potential template that may be adapted locally.

Understanding My Baby's Transition:

- ☐ I know why my baby needs to be moved for their care.
- ☐ I know how, when and where the transfer is likely to happen.
- ☐ I have met (or been introduced to) the new paediatric team and the environment.

Knowing My Baby's Medical Needs:

- ☐ My baby has an Infant Passport that I have co-created with the support of the neonatal team
- ☐ I have a copy of my baby's medical summary.
- ☐ I know what medications my baby is on and why.
- ☐ I understand my baby's feeding plan (intravenous, oral, nasogastric tube, special formula, etc).
- ☐ I understand any equipment my baby needs (oxygen, monitor, pumps, etc).
- ☐ I understand that the above plans may change but I can speak to the new team.

Learn Personalised Emergency Plans:

- ☐ I know the warning signs to watch for (breathing, feeding, colour changes).
- ☐ I know who to call if I am worried about my baby.
- ☐ I have been trained and practiced what to do in an emergency for my baby (for discharge home).

Practical Hands-On Care:

- ☐ I am supported and experienced in feeding my baby.
- ☐ I have been trained and practiced giving appropriate medications, if relevant.
- ☐ I have been trained and practiced using any special equipment, if relevant.
- ☐ I feel comfortable changing, settling, and comforting my baby.

Emotional Support:

- ☐ I know who to contact for support.
- ☐ My feelings about the transition are being heard and respected.
- ☐ I know it is normal to feel excited, scared, and everything in between.

Extra Support (as needed):

- ☐ I have help for mental health, housing, financial concerns (as needed).
- ☐ The healthcare team are aware of if I need an interpreter and/or cultural support.

Final Check:

- ☐ I understand and feel prepared to take this next step.
- ☐ I know who to talk to about any concerns now or in the future.

Appendix 5: Neonatal to Paediatric Care Transition Toolkit

Information for local adaptation.

Toolkit Objectives

- Standardise the transition process from neonatal to paediatric care.
- Support safe handovers and ensure continuity of care.
- Equip staff with essential resources and references.

1. Transition Checklist

To support a holistic handover using a transition checklist promotes safer, more efficient handovers that are increasingly standardised; this helps teams to deliver consistent, high-quality care as families move through inpatient care and can increase provider and parental satisfaction.
**Please note that some of this information may be covered in the medical discharge summary and may be amended to suit your service.*
Include in every handover:

- **Demographics**: Establish Preferred Name, Date of Birth, Corrected Age, Gestation and Birth Weight
- **Holistic Team Working:** Ensure a list of key professionals involved and contact details
- **Admission Summary**: Clarify reason for neonatal admission and key interventions
- **Key Diagnoses**: e.g., CLD, NEC, HIE, IVH, etc.
- **Medication Summary**: Full details of all current medicines, including established plans (e.g., dose titrations, course lengths, and review dates). Neonatal and paediatric pharmacy review ensures formulation-specific considerations, administration techniques, and ongoing supply arrangements.
- **Immunisations**: Status and schedule
- **Nutrition and feeding Plan**: Define current feeding plan with goals and recommendations from Dietitian/Speech and Language Therapist/Infant Feeding Lead. For babies receiving PN, pharmacists from neonatal and paediatric teams should be involved to ensure availability of a suitable PN formulation post-transition.
- **Developmental Plan**: Establish AHP and MDT developmental plans or involvement e.g. neuro-developmental ward round, developmental concerns, postural and play activity plans, plans to progress oral feeding.
- **Parental Voice/Current participation**: Establish resources and approaches in place to support FI-Care and engagement.
    - Establish whether there is an Infant Passport and/or competency document
- **Growth Parameters**: Define current weight, length, head circumference, growth trends
- **Screening Status**: Define retinopathy of prematurity, hearing, newborn blood spot
-
- **Outstanding investigations:** where specific investigations are required that have not been accessed during neonatal care e.g., chest CT scan, bronchoscopy, head MRI
- **Follow-Up Plans**: Establish neurodevelopmental, surgical, cardiac etc and MDT and AHP involvement and AHP follow-up plans and provision including review of community referrals.
- **Social Information**: Include summary on parental engagement, sibling and family support, safeguarding, housing and access issues including parental/guardian involvement in this where appropriate.
- **Cultural and religious considerations:** Identify where are adjustments/input from additional services required to support equitable care.

- **Language, vulnerable/additional needs:** Identify what additional support is required to support equitable access and highlight where there are issues to allow this e.g. interpreter access.
- **Social Care:** Handover child in need/safeguarding plans.

2. Guidance for Team Transition Policy or Standard Operating Procedure (SOP)

There are multiple benefits to having a policy, guidance or SOP to support the transition process including supporting consistency, accountability, patient safety and high quality care. It can provide clarity on communication and responsibility, expectations between teams and team members, and describe data required for audit trails. Any policies should be reviewed regularly and adapted based on feedback, recent and emerging evidence base and evolving clinical guidelines.

- **Reason for transfer:** for transition to paediatrics.
- **Children's Ward Destination:** for primary area of need.
- **Timing & Planning**: Define when and how transitions should be initiated, inclusion of a communication plan that is inclusive of professionals and parents/family.
- **Roles & Responsibilities**:
    - <u>Neonatal Team</u>: Prepare detailed handover and discuss with family, where possible professionals should ensure that they hand over to their own professional group. Where possible, if professionals are on the same site and staffing capacity allows arrange for an initial joint session (for example, a joint goal setting therapy session with parents, baby, neonatal OT and LTV OT).
    - <u>Paediatrics Team:</u> Review and verify understanding of care needs. Identify any areas of additional support/education and facilitate ward visit for family. It may be necessary to establish if any additional training or support is needed for family members.
- **Parental Involvement:**
    - <u>Partnership:</u> Articulate how you are providing families with the right information at the right time; facilitating active participation and to provide feedback in the process.
    - <u>Transparency and Integrity</u>: Define how you are modelling a culture that actively seeks out family voice and establishing parental expectation.
    - <u>Listening, responsiveness and proactivity</u>: Explain how you are using flexible and accessible communication and empowerment supporting families to visit their new wards and teams.
    - <u>Equity and Inclusivity:</u> Demonstrate consideration of 'competencies', education and support to enable families to develop and maintain in their leading of caring for their baby before, during and after transition.
- **Interprofessional Working:**
    - Collaborative working within and across neonatal and paediatric teams ensures continuity of care, shared expertise, and a holistic approach to complex patient needs, ultimately improving outcomes and family experience.
    - Recognising and managing conflict, particularly when differences in expectations arise, is essential to maintain trust, protect patient safety, and support consistent, compassionate care across multidisciplinary teams and optimise their effectiveness.
    - Cross-sector working such as engaging Health Visitors, local and regional charities, peer support and activity groups can provide valuable resources for staff and families.

3. Learning Resources

Case example

Local services can consider providing their own case study(ies) for illustrative purposes. Appendix 6 offers a model as an example.

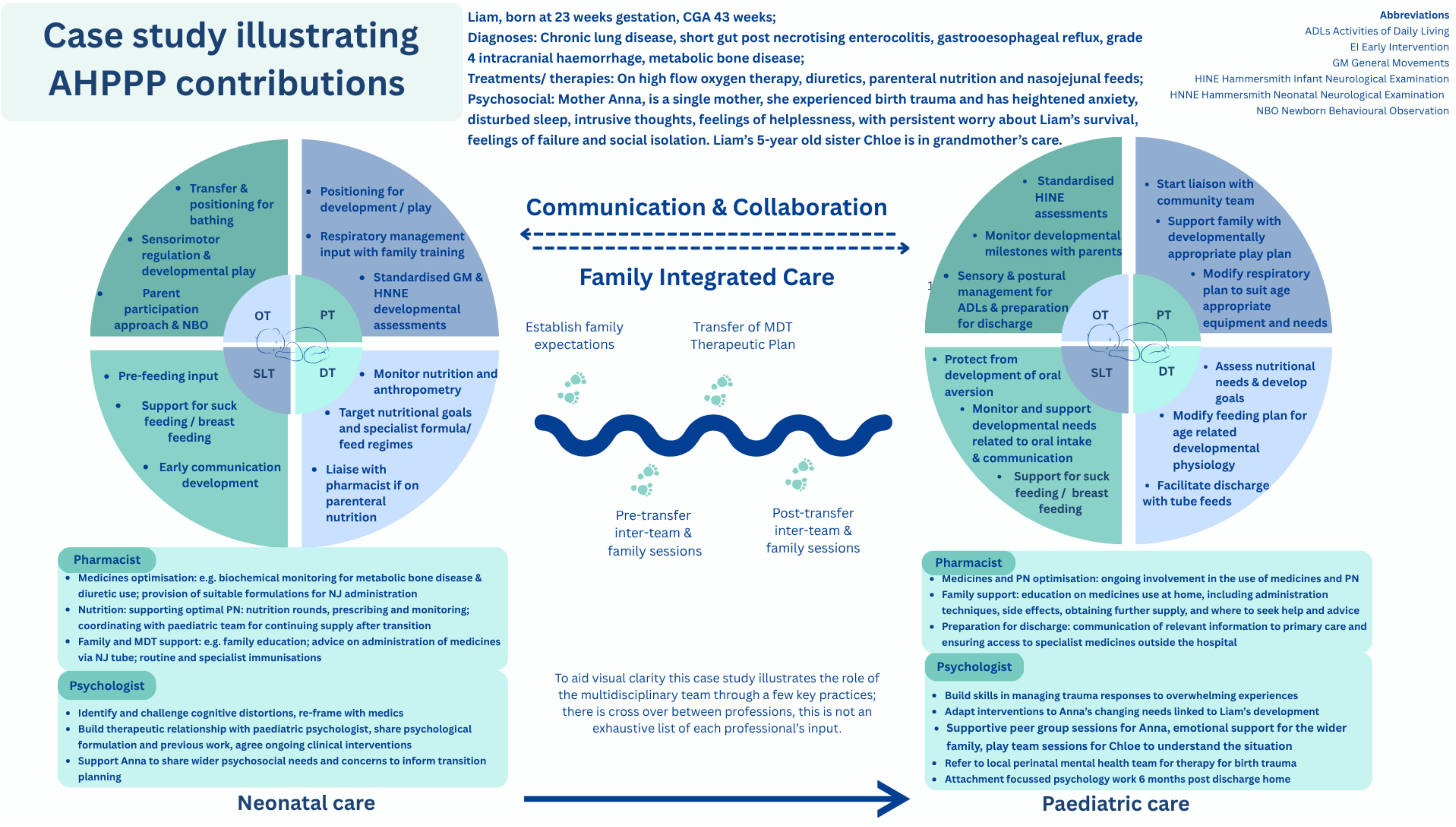
Publications

- **'Interventions to improve team effectiveness within healthcare: a systematic review of the past decade'.** Buljac-Samardzic, van Wijngaarden and Doekhie (2020). *Human Resources for Health.*
- **'Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illnesses'.** Ann F. Schrooten, Barry P. Markovitz (2021). *Copernicus.*
- **'Disagreements in the care of critically ill children'**. *Nuffield Council on Bioethics.*
- **'Teamwork in the neonatal intensive care unit'.** Barbosa (2013). *Physical and Occupational Therapy in Pediatrics.*
- **'Effect of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta synthesis and narrative synthesis'.** Labrie et al. (2021). *Patient Education and Counselling.*
- **'Implementing Potentially Better Practices for Multidisciplinary-team Building. Creating a neonatal intensive care unit culture of collaboration'.** Brown et al (2003). *Pediatrics.*
- **'Crucial Conversations. Third Edition: Tools for Talking When Stakes Are High'.** – Grenny et al. (2021).
- **'The Five Dysfunctions of a Team'.** Patrick Lencioni (2002). Offers insights into the challenges of teamwork and how to overcome them.
- **'Breastfeeding the Brave'.** Lyndsey Hookway (2022). Highlights the needs and challenges of breastfeeding medically complex infants and children in paediatric environments.
- **'Don't Delay the Play'.** A poster for parents and carers to support them with developmental play with their children whilst they are in hospital. https://www.newcastle-hospitals.nhs.uk/services/dont-delay-the-play/
- **UNICEF Standards for Hospital-Based Children's Services** (2022). Provides support for those tasked with implementing the UNICEF UK Baby Friendly Initiative standards for hospital-based children's services.
- **Ash Ruddy | International Family Integrated Care Conference 2025.** https://www.youtube.com/watch?v=rMA-IUZCk-Q

Training and development resources

- **eLearning for Healthcare (UK) – Neonatal AHP Modules**. Introduction to Allied Health Professionals in Neonatal Care - elearning for healthcare
- **Conflict Management: Understanding and managing conflict in children's healthcare.** NHS
- **Institute for Healthcare Improvement (IHI): TeamSTEPPS Tools for NICUs**. Structured tools to improve interdisciplinary teamwork https://www.ihi.org

Appendix 6: Case study illustrating AHPPP contributions



Case study illustrating AHPPP contributions

Liam, born at 23 weeks gestation, CGA 43 weeks;
Diagnoses: Chronic lung disease, short gut post necrotising enterocolitis, gastrooesophageal reflux, grade 4 intracranial haemorrhage, metabolic bone disease;
Treatments/ therapies: On high flow oxygen therapy, diuretics, parenteral nutrition and nasojejunal feeds;
Psychosocial: Mother Anna, is a single mother, she experienced birth trauma and has heightened anxiety, disturbed sleep, intrusive thoughts, feelings of helplessness, with persistent worry about Liam's survival, feelings of failure and social isolation. Liam's 5-year old sister Chloe is in grandmother's care.

Abbreviations
ADLs Activities of Daily Living
EI Early Intervention
GM General Movements
HINE Hammersmith Infant Neurological Examination
HNNE Hammersmith Neonatal Neurological Examination
NBO Newborn Behavioural Observation

Neonatal care

OT
- Transfer & positioning for bathing
- Sensorimotor regulation & developmental play
- Parent participation approach & NBO

PT
- Positioning for development / play
- Respiratory management input with family training
- Standardised GM & HNNE developmental assessments

SLT
- Pre-feeding input
- Support for suck feeding / breast feeding
- Early communication development

DT
- Monitor nutrition and anthropometry
- Target nutritional goals and specialist formula/ feed regimes
- Liaise with pharmacist if on parenteral nutrition

Pharmacist
- Medicines optimisation: e.g. biochemical monitoring for metabolic bone disease & diuretic use; provision of suitable formulations for NJ administration
- Nutrition: supporting optimal PN: nutrition rounds, prescribing and monitoring; coordinating with paediatric team for continuing supply after transition
- Family and MDT support: e.g. family education; advice on administration of medicines via NJ tube; routine and specialist immunisations

Psychologist
- Identify and challenge cognitive distortions, re-frame with medics
- Build therapeutic relationship with paediatric psychologist, share psychological formulation and previous work, agree ongoing clinical interventions
- Support Anna to share wider psychosocial needs and concerns to inform transition planning

Communication & Collaboration

Family Integrated Care

Establish family expectations

Transfer of MDT Therapeutic Plan

Pre-transfer inter-team & family sessions

Post-transfer inter-team & family sessions

To aid visual clarity this case study illustrates the role of the multidisciplinary team through a few key practices; there is cross over between professions, this is not an exhaustive list of each professional's input.

Paediatric care

OT
- Standardised HINE assessments
- Monitor developmental milestones with parents
- Sensory & postural management for ADLs & preparation for discharge

PT
- Start liaison with community team
- Support family with developmentally appropriate play plan
- Modify respiratory plan to suit age appropriate equipment and needs

SLT
- Protect from development of oral aversion
- Monitor and support developmental needs related to oral intake & communication
- Support for suck feeding / breast feeding

DT
- Assess nutritional needs & develop goals
- Modify feeding plan for age related developmental physiology
- Facilitate discharge with tube feeds

Pharmacist
- Medicines and PN optimisation: ongoing involvement in the use of medicines and PN
- Family support: education on medicines use at home, including administration techniques, side effects, obtaining further supply, and where to seek help and advice
- Preparation for discharge: communication of relevant information to primary care and ensuring access to specialist medicines outside the hospital

Psychologist
- Build skills in managing trauma responses to overwhelming experiences
- Adapt interventions to Anna's changing needs linked to Liam's development
- Supportive peer group sessions for Anna, emotional support for the wider family, play team sessions for Chloe to understand the situation
- Refer to local perinatal mental health team for therapy for birth trauma
- Attachment focussed psychology work 6 months post discharge home

References

1. Costeloe KL, Hennessy EM, Haider S, Stacey F, Marlow N, Draper ES. Short term outcomes after extreme preterm birth in England: comparison of two birth cohorts in 1995 and 2006 (the EPICure studies). BMJ 2012:345:e7976.
2. Smith LK, Draper ES, Manktelow BN, Fenton A, Kurinczuk J on behalf of the MBRRACE-UK Collaboration. MBRRACEUK Report on survival up to one year of age of babies born before 27 weeks gestational age for births in Great Britain from January to December 2016. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester. 2018.
3. Myrhaug HT, Brurberg KG, Hov L, Markestad T. Survival and impairment of extremely premature infants: a meta-analysis. Pediatrics 2019;143:e20180933
4. Victoria Coathup, Elaine Boyle, Claire Carson, Samantha Johnson, Jennifer J Kurinczuk, Alison Macfarlane, Stavros Petrou, Oliver Rivero-Arias, Maria A Quigley. Gestational age and hospital admissions during childhood: population based, record linkage study in England (TIGAR study). BMJ 2020;371:m4075 | doi: 10.1136/bmj.m4075.
5. Tim J van Hasselt, Chris Gale, Cheryl Battersby, Peter J Davis, Elizabeth Draper, Sarah E Seaton. Paediatric intensive care admissions of preterm children born <32 weeks gestation: a national retrospective cohort study using data linkage. Arch Dis Child Fetal Neonatal Ed 2024;109:F265–F271. doi:10.1136/archdischild-2023-325970.
6. Sarah E Seaton, Cheryl Battersby, Peter J Davis, Alan C Fenton, Josie Anderson, Tim J van Hasselt, Elizabeth Draper. Characteristics of children requiring admission to neonatal care and paediatric intensive care before the age of 2 years in England and Wales: a data linkage study. Arch Dis Child. 2024 Apr 18;109(5):387-394. doi: 10.1136/archdischild-2023-325986.
7. Tim J van Hasselt, Suzy Newman, Hari Krishnan Kanthimathinathan, Peter J Davis, Elizabeth S Draper, Chris Gale, Cheryl Battersby, Sarah E Seaton, The United Kingdom Neonatal Collaborative and the Paediatric Critical Care Society Study Group (PCCS-SG). Transition from neonatal to paediatric intensive care of very preterm-born children: a cohort study of children born between 2013 and 2018 in England and Wales. Arch Dis Child Fetal Neonatal Ed 2024;0:F1–F8.
8. The National Confidential Enquiry into Patient Outcome and Death. 'The Inbetweeners' 2023. London doi:10.1136/archdischild-2024-327457.
9. POPPY Steering Group. Family-centred care in neonatal units. A summary of research results and recommendations from the POPPY project. London: NCT; 2009
10. Sarah E Seaton, Joseph C Manning, Gillian Colville, Nicola Mackintosh. Creating a home with a critically ill child: A qualitative study exploring the experiences of parents of children admitted to paediatric critical care following treatment in neonatal care. Aust Crit Care 2025 Jan;38(1):101101, doi: 10.1016/j.aucc.2024.07.082.
11. Roy Evans MS, RN, NNP, Beth Madsen. Culture Clash: Transitioning from the Neonatal Intensive Care Unit to the Pediatric Intensive Care Unit. Newborn and Infant Nursing Reviews, Vol 5, Issue 4, Dec 2005,188-193, https://doi.org/10.1053/j.nainr.2005.08.005.
12. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. RCPCH 2015. https://adc.bmj.com/content/archdischild/100/Suppl_2/s1.full.pdf
13. Recognising uncertainty: an integrated framework for palliative care in perinatal medicine. July 2024. https://www.bapm.org/resources/palliative-care-in-perinatal-medicine-framework
14. https://learninghub.nhs.uk/Catalogue/Recognising-and-managing-conflict-between-childrens-

families-and-healthcare-providers

15. https://www.nuffieldbioethics.org/publication/independent-review-disagreements-in-the-care-of-critically-ill-children/
16. https://www.england.nhs.uk/wp-content/uploads/2015/01/Neonatal-critical-care-service-specification-March-2024.pdf
17. https://www.bapm.org/resources/service-and-quality-standards-for-provision-of-neonatal-care-in-the-uk
18. https://www.bapm.org/resources/296-optimal-arrangements-for-neonatal-intensive-care-units-in-the-uk-2021
19. https://static1.squarespace.com/static/6627aa0395e1c02ebbda8cca/t/66df11f309d7a67dc20d1133/1725895159523/PCCS-Standards-2021.pdf
20. https://www.abpn-uk.com/uploads/4/3/1/2/43121793/standards_for_safe_staffing_in_children_and_young_peoples_wards_and_departments.pdf
21. https://www.bda.uk.com/static/ab614d3e-e095-4e4f-96ae1458204e8810/391a27be-69a0-4b43-a52d54a731da7f01/BDA-Formatted-Staffing-Recc.pdf
22. https://nppg.org.uk/wp-content/uploads/2022/10/NPPG-Neonatal-Staffing-Standards-V2.pdf
23. https://www.rcslt.org/wp-content/uploads/2023/03/Neonatal-staffing-levels-2025-Final.pdf
24. https://www.rcot.co.uk/explore-resources/rcot-publications/occupational-therapy-staffing-neonatal-units
25. https://apcp.csp.org.uk/system/files/documents/2023-09/2023_apcp_physiotherapy_staffing_recommendations_for_neonatal_units_in_the_uk.pdf
26. https://acpuk.org.uk/member-networks/psychology-staffing-on-the-neonatal-unit-2/
27. https://www.bapm.org/resources/neonatal-outreach-service
28. Malouf R., Harrison S., Burton H.A.L, Gale C, Stein A, Franck L.S, et al. Prevalence of anxiety and post-traumatic stress (PTS) among the parents of babies admitted to neonatal units: A systematic review and meta-analysis. E Clinical Medicine, 43, 101233
29. Substance Abuse and Mental Health Authority (2014). SAMHSA’s Concept of Trauma and Guidance for a Trauma-Informed Approach. Department for Health and Human Services, USA. https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4884.pdf
30. Sanders MR., Hall SL. Trauma-informed care in the newborn intensive care unit: promoting safety, security and connectedness. Journal of Perinatology 2018; 38, 3 – 10
31. https://www.england.nhs.uk/publication/a-good-practice-guide-to-support-implementation-of-trauma-informed-care-in-the-perinatal-period/
32. https://www.bapm.org/resources/ficare-framework-for-practice
33. https://www.england.nhs.uk/publication/implementing-the-recommendations-of-the-neonatal-critical-care-transformation-review/

BAPM

Leading Excellence in Perinatal Care

This document was produced by the British Association of Perinatal Medicine (BAPM).

BAPM is a membership organisation that is here to support all those involved in perinatal care to optimise their skills and knowledge, deliver and share high-quality safe and innovative practice, undertake research, and speak out for babies and their families.

We are a professional association of neonatologists, paediatricians, obstetricians, nurses, midwives, trainees, network managers and other health professionals dedicated to shaping the delivery and improving the standard of perinatal care in the UK.

Our vision is for every baby and their family to receive the highest standard of perinatal care. Join us today.

www.bapm.org/join

British Association of Perinatal Medicine (BAPM)
is registered in England & Wales
under charity number 1199712 at
5-11 Theobalds Road, London, WC1X 8SH