

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

A DRAFT BAPM Framework for Practice

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Contents

Members of the working group	3
Process of framework development	4
Key recommendations	5
ntroduction	7
Glossary	8
Pathways from neonatal care	8
Process of transition	12
Multidisciplinary teams	18
Family support	20
Transfer of information	24
Recommendations for future work	26
Appendix 1: Transition from neonatal to paediatric services: summary of MDT involvement and coordination	27
Appendix 2: MDT meeting standard agenda template	31
Appendix 3: Neonatal to Paediatric Care Transition Toolkit	32
Appendix 4: Parent Information Leaflet guidance	35
Appendix 5: Parental Transition Checklist - Moving from Neonatal Care to Paediatrics	36
Appendix 6: Case study illustrating AHPPP contributions	37
References	38

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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.

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 uses 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 patient 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 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 multi-disciplinary team approach, with collaborative input from medical, nursing, allied health professionals, psychology, pharmacy and other support staff across clinical services is essential.

Coordination and delivery of care

- 4. There should be a named responsible consultant for all subspecialties involved (e.g., neonatology, respiratory, critical care, paediatric surgery), 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's most significant medical condition(s) should be responsible for coordinating healthcare wherever the baby is located.
- 6. Each Trust should have a process that supports the coordination of transition, including identification of a transition coordinator for each baby, 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 multi-disciplinary planning meetings before and after transfer, involving families, neonatal services and involved paediatric services.

Families

- 8. Parents must be recognised as equal partners in their baby's care and decision-making, regardless of their baby's location, reflecting their expertise in their baby's care. This should be recognised in documents that provide assurance of the parents' skills in assisting with care.
- 9. Families should be cared for using a trauma-informed and family-integrated (FICare) approach.

Communication

- 10. Robust handover of information is essential, including verbal handover at a senior level between teams. Comprehensive standardised transition paperwork will 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.
- 11. 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

- 12. Trusts and Operational Delivery Networks (ODNs) should collaborate to develop pathways of care, governance and review processes including audit standards to support effective transition for babies moving within and between hospitals, across regions and network boundaries.
- 13. 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 and ODNs should consider developing joint working and/or training opportunities with neonatal, paediatric and paediatric critical care teams to achieve this.
- 14. There should be local and regional review of staffing capacity and demand to support transition, in particular nursing and AHPPP services to ensure 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, longer term tube feeding, and require extended and ongoing inpatient and outpatient care.

The most medically complex babies being discharged from neonatal units will benefit from a transition pathway from NICUs to paediatric services. Though 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), 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 (12-14).

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.

This 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.

This framework will not include routine neonatal discharge pathways, regular outpatient care, health care involving a single subspecialty, or palliative care pathways.

Glossary

ACP Advanced 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

LLC Life-limiting conditions
LNU Local Neonatal Unit
LTV Long term ventilation
MDT Multi-Disciplinary 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

PICU Paediatric Intensive Care Unit

PMA Post-menstrual age
PN Parenteral nutrition
PT Physiotherapy/therapist
PPC Paediatric Palliative Care

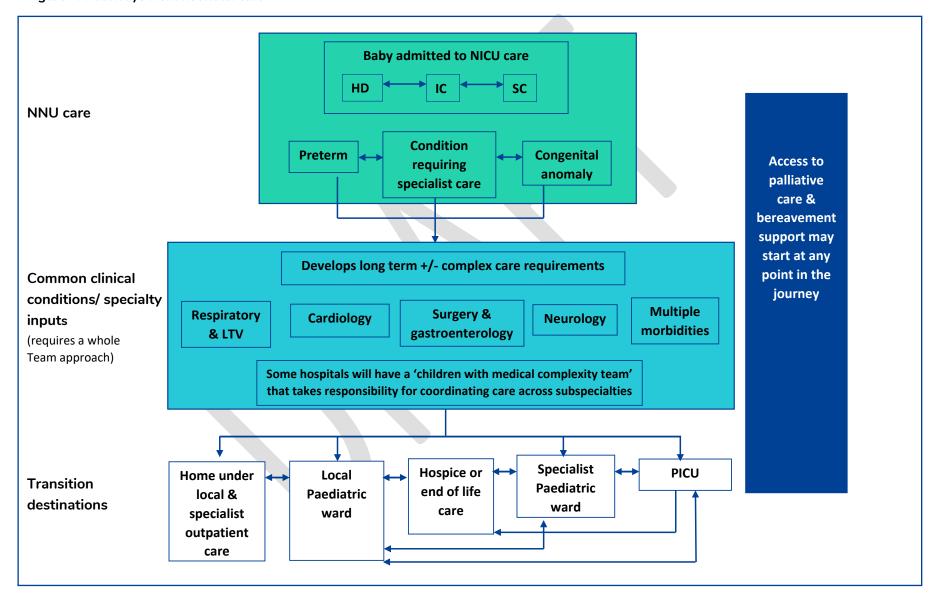
RCPCH Royal College of Paediatrics and Child Health SLT Speech and Language Therapy/Therapist

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 multi-disciplinary input from a team or teams of medical, nursing and AHPPPs. Figure 1 illustrates potential pathways.

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.

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 burden 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 Parent and Family Support section.

Figure 1 illustrates some medical and surgical conditions in newborns that will need to transition. Appendix 1 provides more detail and MDT involvement.

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 Children with medical complexity team.

Children with life-limiting conditions (e.g., 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 interest' discussions.

Transition destinations

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

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) paediatric wards.

Specialist Paediatric ward

Babies with organ-specific conditions will usually transition to the appropriate subspecialty ward. 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).

General paediatrics

This pathway is usually for babies who have "outgrown" the neonatal unit and need repatriation to their local hospitals. They require ongoing low dependency, or in some cases high dependency inpatient care.

Home

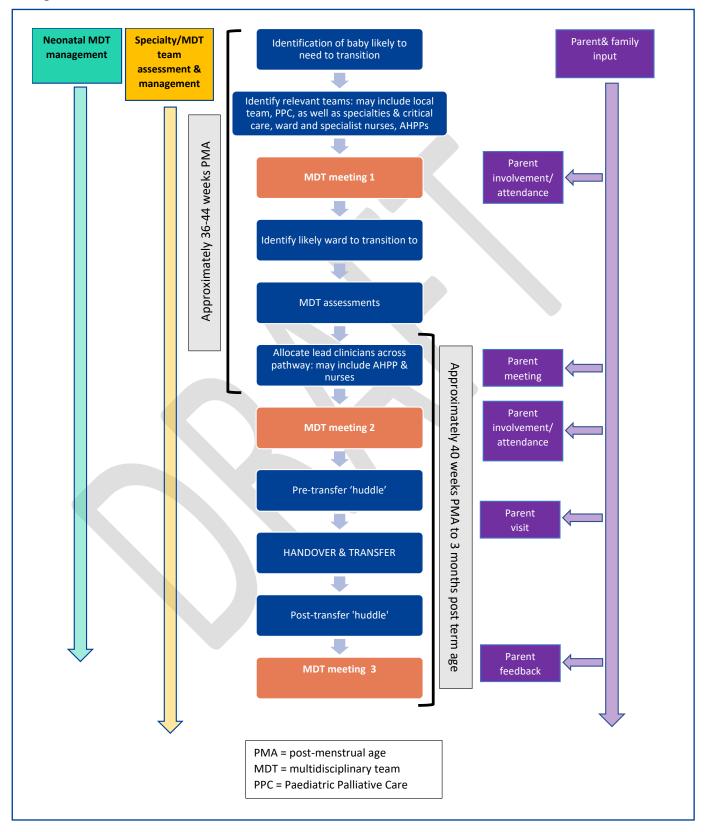
Babies going home with significant ongoing healthcare needs requiring subspecialist input and with a high likelihood of readmission, either to the local or specialist hospital.

Hospice and end of life care

Babies who are considered to have potentially life-limiting conditions, transition may occasionally include planning for end-of-life care. Refer to 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine, a BAPM Framework for Practice' (12).

Process of transition

Figure 2. Process of transition



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)' (15).

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).

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 CGA

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 related transition pathways, and to admission to Paediatric wards, including paediatric 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 may be using equipment unavailable on paediatric critical care wards and not be able to use paediatric equipment made for portable ventilators due to their small size.

Safety

It may be preferred for babies with chronic lung disease not to be transferred to paediatric wards during winter due to the risk of exposure to viral respiratory illnesses.

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, 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, including 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 the General paediatric team from the baby's local hospital early.
- 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.
- Referral to and involvement of the palliative care team for parallel planning will be appropriate for some babies (12).

"Helpful to have an MDT beforehand (usually via teams) to discuss prognosis etc and ensure that everyone is one 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.
- 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. Families may appreciate an extended time orientating themselves to the new ward.
- Medical and nursing staff from the receiving paediatric service should visit the family on NICU if
 they are not already involved in the multi-disciplinary 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 coproduced with the parents and commenced early in the process of gathering information.
- A written record of parents' skills in aspects of the baby's care (e.g., stoma care, tube feeding) 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.

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.
- 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 questions down, 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.
 - Invite parents 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 inperson 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 child's wider developmental needs are understood. Attendance by pharmacists
 should be invited for babies who require parenteral nutritional expertise or complex
 medications.
- 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 psychologist(s) is important.
- Include the specialist neonatal/paediatric transport team that will undertake the transfer at the confirmatory MDT meeting if the baby will need 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 pretransfer 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 the region 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, with information on relevant clinical events, growth charts, and medical, nursing and

- AHPPPs' plans. Receiving teams should also have access to the relevant Infant Passport and any documentation of parent competencies (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; otherwise, loss of information is inevitable.
- 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.
- Any 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.

Longer term aspects post-transition

- Many of these children 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 may consider having conversations with families about the possibility of future admission(s) to paediatric hospital. It may be helpful to build an awareness in a similar way to preparing families transitioning directly to paediatric inpatient services.
- Additional important considerations:
 - Community paediatric services provide multi-disciplinary support for babies with complex care needs, including extremely prematurely born babies.
 - Universal services (e.g., General Practitioners and Health Visitors) form an important part of the team around the child. Families may need referral to social care support.
 - Babies with ongoing complex care needs will often require assessment to inform home care package provision.
 - Housing is an important consideration, especially if a child has significant technology dependence or home requirements.

Monitoring and improving transition

- Neonatal and paediatric services within hospitals and regions should collaborate to improve transition pathways. 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 quality improvement approach applied to guidelines, pathways, clinical audit, 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, 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 standards available for medical and nursing staff in neonatal and paediatric inpatient care units, including critical care (16-18); and for AHPPP staffing for neonatal critical care (19-24). 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 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 (15, 16, 25). 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.
- 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.

"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.

Appreciating the context of their parenting experiences

By the time of transition, parents are experts on their own baby. Healthcare professionals should embrace the families' significant knowledge, expertise and skills and actively elicit their opinions and concerns as equitable partners. This includes, but is not limited to, being able to provide care (e.g., tube feeding) and knowing how best to comfort and soothe their child.

"The Paediatric team treated us like a couple of 16-year-olds who never had a baby in their hands before, despite us having just spent the last 18 weeks caring for her around the clock and becoming the encyclopedia of our daughter. We were dismissed, patronised and it was hard to state what our concern was without getting constantly interrupted. We miss the NICU doctors who trusted us to know exactly what is going on with our daughter and that we could be relied on as a source of information for her."

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 specific needs (e.g., literacy, cognitive impairment, neurodiversity).
- Consider if families have any wider social needs (e.g., housing, education, employment, finance).
- Consider the needs of siblings as appropriate to their age and development.
- 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 pediatric ward.

- Assigning a 'transition buddy': A key worker who checks in regularly before and after the move.
- Including touches of familiarity in a new environment: Learn about a family's NICU 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 (26). 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 (27):

- 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 minimize 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 child 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 (28), and in the NHSE good practice guide (29).

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, family involvement, and assumptions about care.

Whilst all services aim for child wellbeing, 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.

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."

"[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."

*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 (30). Following recommendations from the Neonatal Critical Care Transformation Review in 2019 (31), 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 (30).

"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. This was especially the case on PICU where we were actively excluded from ward rounds and our opinions were not sought on any matters. Excluding the parents/carers from ward rounds is such an archaic and, in my opinion, egotistic, practice."

Communication with families

An empathetic, open professional relationship with personalised communication using preferred terminology (e.g., using names rather than "baby" or "mum"), may provide 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."

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 and hospitals, 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 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, 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, developmental, and family concerns) is shared across settings.
- A verbal, face-to-face handover at the time of transfer is essential so that clinical professionals taking over care at the baby's bedside receive all the important information. 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 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.

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, 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 this information:

The child

- 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, enteral tube feeding; 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.
- 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.
- What is important to us and our family (e.g., spiritual/cultural/communication needs).
- What our wider support network consists of.

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.

Parent competency documentation

A documented record of the parents' competence to provide specific aspects of care, such as stoma care, 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. Better delineation of the numbers of babies who transition into Paediatric services, with information on neonatal, paediatric and critical care perspectives.
 - b. Parents' experience of babies with complex transition journeys.
- 2. Neonatal and Paediatric ODNs and commissioning organisations should assess capacity requirements, funding and commissioning of appropriate services for babies requiring transition, particularly for babies requiring ongoing critical care and children with medical complexity.
- RCPCH should look to 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, and seek to improve understanding between health care professionals in
 neonatal and paediatric critical care services.
- 4. Royal Colleges, specialty staff groups, ODNs should look to improve 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 specialty groups should work 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	Reasons for Transition	Specialty Team	Transition Considerations/ Responsibilities
	Conditions		Involvement	
Neonatal Critical Care (NICU, LNU, SCU)	All sick and preterm babies		NNU teams, includes medical & nursing staff, pharmacists, psychologists, PT, OT, SLT, dietitians	Early identification of babies likely to require transition; allocation of responsible consultant; identification of staff member coordinating transition; 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.
Paediatric Critical Care (PICU & HDU)	All sick babies from term age requiring IC or HD; preterm babies from 44 weeks PMA requiring invasive ventilation or high-level NIV	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, PT, pharmacists, psychologists, OT, dietitians, SLT	Early engagement in discussion regarding babies likely to transition. Identification of responsible consultant. Attend MDT meetings. Meet parents prior to transition. Critical care teams should be involved in transition discussions even if the transfer of 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	Babies born extremely preterm with CLD may need prolonged respiratory support. Others with congenital or acquired airway/lung anomalies or neuromuscular disorders may	Respiratory team, includes medical & nursing staff, CNSs; critical care; PT, dietitians, SLT, OT; ENT team	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

		require long-term ventilation (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.		complex airway clearance needs — this may require assistance from critical care staff. Attend MDT meetings. 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, CNSs, psychologists; cardiac surgery; PICU; dietitians, SLT, PT, OT	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 cases. Attend MDT meetings.
Surgery / Gastroenterology	Necrotising enterocolitis; Short bowel syndrome; Intestinal atresia; Abdominal wall defects; TOF/OA	Babies needing nutritional support, stoma care, or 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.	Surgery team, includes medical & nursing staff, CNSs; gastroenterology team, includes medical & nursing staff, CNSs; dietitians, pharmacists, SLT, OT, PT	Define lead specialty for transition. Babies who have been managed by the surgical team may be handed over to gastroenterology for long term care. Allocate responsible consultant. 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. Attend MDT meetings.
Neurological	HIE; Congenital	Need for seizure	Neurology	Define lead specialty early. Plan for long-

	encephalopathies;	management, neurodevelopmental monitoring, complex dietary management, and therapy input. LTV often needed for neuromuscular conditions. Support for severe developmental delay and rehabilitation services required.	team; Neurodisability team; Respiratory team for LTV; PPC. Includes medical & nursing staff, PT, SLT, OT; dietitians; pharmacists	term therapy input. 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	Renal anomalies; Neurosurgical issues; Airway abnormalities; 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; Genetics, Specialty team medical & nursing staff, OT, PT, SLT, dietitians, pharmacists.	Prepare tracheostomy care plans. Allocate relevant specialty lead. 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- system Needs	Multiple anomalies; Prematurity- related complications; Syndromes (e.g., trisomy 13/18)	Ongoing complex care requirements requiring long-term inpatient care, complex discharge arrangements, and outpatient follow-up.	Children with medical complexity team (if available); general paediatrics; specialty teams, including PPC; Teams should include medical & nursing staff, dieteticians, SLT, PT, OT	Require multi-specialty, coordinated care. Transition may be delayed without careful 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		PPC team, including medical & nursing	Allocate responsible consultants. Engage in regular liaison with NNU team. Attend MDT

	transition may be life-limiting		staff, coordinating staff, CNSs, OT, PT, SLT, pharmacists.	meetings. Development of advanced care plans may be necessary before transition to ensure a shared understanding of future aims/
General Paediatric services	Need for inpatient care after term CGA e.g. CLD	Repatriation to local hospitals; Ongoing respiratory care; Establishing feeds; Discharge planning	Local Paediatric team, including medical & nursing staff, OT, PT, SLT, pharmacists, dietitians	Involve the team from the local hospital early, including when babies transition to specialty hospitals/wards. Attend MDT meetings. Liaise with community services and primary care.
Additional conside	erations			
Community Paediatric services	Babies needing complex care post-discharge; Preterm babies & those at risk of neurodevelopmental impairment		Local team, including medical & nursing staff, PT, OT, SLT, pharmacists, dietitians, Portage	Neurodevelopmental surveillance, screening e.g. vision and hearing assessments, MDT support. Ensure appropriate social services involvement. Liaise with Continuing Care teams.
Primary Care services	All babies		GPs, Health Visitors, other practice staff	Ensure completion of immunisations. Identify support offerings in local community. Ongoing oversight of day-to-day issues.

Appendix 2: MDT meeting standard agenda template

- 1. Introduction by the chair, followed by introductions and apologies from MDT members.
- 2. Clarification of transition coordination and parent point of contact.
- 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. Questions invited from parents.
- 10. Questions invited from teams who may not yet be part of the baby's care e.g., critical care, palliative care, children with medical complex care team and local team.
- 11. 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.
- 12. Next steps.
- 13. Allocation of responsibility for documentation and circulation of minutes.
- 14. Planning feedback to parents/carers (if not present in the meeting).

Appendix 3: 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 reference tools.

1. Transition Checklist

To support a holistic handover using a transition checklist promotes safer, more efficient handovers that are increasingly standardised helping 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: CLD, NEC, HIE, IVH, etc.
- Medication Summary: Detail current medications and any recent changes.
- **Feeding Plan**: Define current feeding plan with goals and recommendations from Dietitian/Speech and Language Therapist/Infant Feeding Lead.
- Developmental Plan: Establish AHP and MDT developmental plans or involvement e.g. neurodevelopmental 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 Fl-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
- Immunisations: Status and schedule
- 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, 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. translator access.
- **Social Care:** Handover child in need/child protection plans.

*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 and patient safety. It can provide clarity on communication and responsibility, expectations between teams and team members, and describe data required for audit trails.

- Reason for transfer: for transition to paediatrics
- Paediatric 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:

- Neonatal Team: Prepare detailed handover and discuss with family, where possible professions should ensure that they hand over to their own professional group. Where possible, if professions 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).
- Paediatrics Team: 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:

- Partnership: Articulate how you are providing families with the right information at the right time; facilitating active participation and to provide feedback in the process
- Transparency and Integrity: 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
- Equity and Inclusivity: 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.

3. Learning Resources

- 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.
- Additional consideration is needed for cross-sector working such as access to resources such as local and regional charity peer support, activity groups and resources.

Case example

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

Books, articles and texts

- '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 Counseling.
- '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.

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

Note: This toolkit should be reviewed annually and adapted based on feedback, recent and emerging evidence base and evolving clinical guidelines.

Appendix 4: 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
 - o Acknowledge and normalise the family's likely wide variety of emotions
 - Celebrate the fact their infant is growing up
 - o Acknowledge the important role the family play in the care of their infant
- 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
 - Equipment differences
 - How the days generally work
 - o General care and how that might change as their infant 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 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

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, lessened FiCare and new points of contact.

Appendix 5: Parental Transition Checklist - Moving from Neonatal Care to Paediatrics

This is a potential template that may be adapted locally.

Unders	standing My Baby's Transition:
	I know why my baby needs their care moving.
	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.
Knowii	ng 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 (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 F	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).
D	
	al 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.
	Treel connortable changing, setting, and connorting my baby.
Emotio	onal 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 S	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 C	heck:
	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 6: Case study illustrating AHPPP contributions

Case study illustrating **AHPPP** contributions

Liam, born at 23 weeks gestation, CGA 43 weeks;

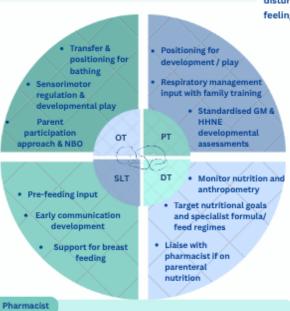
Diagnoses: Chronic lung disease, short gut post necrotising enterocolitis, gastrooesophageal reflux, grade 4 intracranial haemorrhage, metabolic bone disease;

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. 5-year old sister Chloe is in grandmother's care

Abbreviations

ADLs Activities of Daily Living El Early Intervention GM General Movements

HINE Hammersmith Infant Neurological Examination HNNE Hammersmith Neonatal Neurological Examination NBO Newborn Behavioural Observation



Communication & Collaboration

Family Integrated Care

Transfer of MDT Establish family Therapeutic Plan expectations



Pre-transfer inter-team & family sessions

Post-transfer inter-team & family sessions Protect from development of oral

Sensory & postural

management for

ADLs & preparation

- aversion · Monitor and support

- Start liaison with community team
- · Support family with developmentally appropriate play plan
- · Modify respiratory plan to suit age appropriate
- SLT

OT

Standardised

assessments

HINE

Monitor developmenta

milestones with parent

- developmental needs related to oral intake & communication
 - Support for breast feeding
- Assess nutritional needs & develop goals
- · Modify feeding plan for age related developmental physiology
- Facilitate discharge with tube feeds

- · Involvement in nutrition rounds and discussions
- · Supporting parenteral nutrition prescription, administration & monitoring
- . Ensuring provision of medicines, medicines safety and immunisation

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
- . Support Anna to share wider psychosocial needs and concerns to inform transition planning

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

Pharmacist

- . Ongoing Involvement in nutrition provision & monitoring, medicines & medicines safety and immunisation
- · Education of parents for medicines for discharge

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

Paediatric care

Neonatal care

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