Section	Person	Consultation responses	Working Group review comments
Process of framework development	Caroline Nyawira Individual	The framework development process demonstrates commendable engagement with both professionals and families. The inclusion of a Parent and Carer panel and surveys of neonatal and paediatric staff reflects a collaborative and inclusive approach. Future iterations could benefit from broader representation across diverse regions and community-based services to ensure equity of voice.	Thank you. The working group agrees that diversity of voices is vitally important.
	Sally Watts Individual	well presented and explained	Thank you
	Alex Dewar Individual	I think it would be helpful to set out clearly why the review was required and what the goals of any recommendations are as part of the framework development. Utilising staff survey data is legitimate, but by clearly articulating why the review was commissioned with additional data demonstrating the difficulty, it may help contextualise and frame the recommendations. Perhaps a box which highlights goals, challenges and potential solutions might make this clearer.	Thank you. The working group thinks that the introduction sets out the challenges of this patient pathway for staff and families clearly, with problem-based solutions embedded throughout.
	Sharon Breward Individual	This document appears to omit reference to breastfeeding/Infant feeding/lactation care - there appears to be no Infant Feeding/Lactation Specialist on the working Group & there is no reference to the breastfeeding/Infant feeding/lactation care team in the list of services involved in care	Thank you for all your comments regarding infant feeding. The working group agrees the importance of feeding support in this vulnerable group. Although the constraints of the working group process precluded wider membership than already provided, we feel that the SLT and dietetic input provided important expertise when we considered infant feeding. References to infant feeding support have been enhanced in the following areas:

			‘Infant feeding’ added to ‘relevant clinical information’ in ‘Transfer and immediate approach post-transition'. Who makes up a team? ‘Infant feeding specialists’ added Understanding the parents’ perspective. Edit changing to ‘feeding, including tube feeding’ Clinical communication. ‘Infant feeding support’ added. Addition of infant feeding team in appendix 1. Addition of ‘Breastfeeding the Brave’ and the UNICEF hospital-based children’s service standards have been added to the resources in appendix 3.
	Francesca Seregni Individual	I think it would be good to have community paediatricians or neurodisability paediatricians part of the core working group. Similarly, I also think input from BACD members would be important.	The working group agrees the importance of community paediatric and neurodisability support in this vulnerable group and feel that this is reflected in the ‘Longer term aspects post-transition' section and in Appendix 1 ‘Transition from neonatal to paediatric services: summary of MDT involvement and coordination’. Although the constraints of the working group process precluded wider membership than already provided, applications for the paediatric subspecialty representative on the group were elicited from all areas of paediatric subspecialisation.
	Joanne Stout On behalf of CDDFT	The membership group we thought was very limited to NICU and PICU teams (inc. AHPP) and although does state a survey was sent to paediatric services, they are not represented in the working group. No representative outside above teams from RCPCH.	Thank you for your comments. The application process for working group membership was open to all paediatricians and the working group included a general paediatrician and a subspeciality paediatrician.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	The working group have clearly followed a process to get feedback from professionals and families about their experiences of transition from neonatal to paediatric care, although it is disappointing that there was no DGH general paediatrician or palliative care	Thank you for your comments. Although the constraints of the working group process precluded wider membership than already provided, applications for the paediatric subspecialty representative on the group were elicited from all areas

		clinician in the group and the parent and carer panel was only made up of 4 people in sections of the framework the phrase "many families" however it is not clear whether this has come from the working group or published work. With such a small number of families in the working group there is a risk of some bias with only those who have had a negative experience wanting contribute. It may have been beneficial to have had a general paediatrician within the working group to offer a perspective of care from paediatric services outside of critical care.	of paediatrics. The application process for working group membership was open to all paediatricians and the working group included a general paediatrician and a subspeciality paediatrician. The academic representative has a significant body of published work on parent and family experience. The working group also conducted some additional family engagement work, which we hope to publish in the future. The working group recognises the valuable contribution of palliative care professionals in this area and the importance of the MDT utilising the comprehensive BAPM's 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine'. All relevant paediatric subspecialty bodies, including the Association of Paediatric Palliative Care Medicine, were asked for feedback during the consultation process.
	Laura Nohavicka and Christine Mott on behalf of APPM	It is a shame that although palliative care is frequently mentioned in the guideline, none of the members of the working group are palliative care specialists.	Although the constraints of the working group process precluded wider membership than already provided, applications for the paediatric subspecialty representative on the group were elicited from all areas of paediatrics. The working group recognises the valuable contribution of palliative care professionals in this area and the importance of the MDT utilising the comprehensive BAPM's 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine'.

Key recommendations	Fola Egbewole Individual	Some acknowledgment that maternity and neonatal there is huge disparity in equity. Under 8. Families - can there be eloboration on Fi Care? We know this should be the standard but unfortunately it's sometimes very difficult. e.g. neonatal unit - mother with one child inpatient, has older child and no childcare, situated a while away from NNU (as local does does not provide Level 3 care) how is this mother also included in FiCare? Suggestion - telephone/video call/iPad updates, option to see daily medical notes and ask questions to the team remotely	Thank you. Recommendation 9 has been updated to specify that families should be cared for using a 'culturally sensitive' approach. An additional recommendation has been made around addressing 'barriers that may limit parents' ability to actively contribute to their baby's care'.
	Caroline Nyawira Individual	The recommendations are well-structured and actionable. Emphasis on MDT coordination, family-integrated care, and robust handover processes is particularly strong. Additional recommendations could include staff wellbeing protocols, digital interoperability standards, and emergency transition protocols.	Thank you. Digital communication is emphasised in the 'Discharge documentation' section of the document. The recommendation has been changed from 'paperwork' to 'documentation'. An 'Acute or unplanned transfer' subsection has been added to the Process section of the document. The importance of staff wellbeing has been added to 'Teams and teamworking'.
	Bala Subramaniam Individual	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. The above section to include General Paediatrician as a joint responsible physician.	Thank you for your comment. This recommendation has been changed to reflect this.
	sally watts	well presented and explained	Thank you

	Individual		
	Alex Dewar Individual	The recommendations seem appropriate and involvement of named consultants on a per specialty basis seem sensible. It is not clear what which performance indicators of quality care the recommendations are trying to improve. To my mind - teams should work together better is valid prima facie, but a lack of clear signalling for which outcomes we are trying to improve or risks we are trying to mitigate, hamstrings the impact of such recommendations. Is the review aimed at staff so that we treat each other better (known well-worn conflict between NICU and PICU teams), or is this a call to action for policy makers and ODN's to increase support and funding for a growing population of medically complex children with exceptional needs? I think this could be clearer. The report should recommend key performance indicators of quality against which services can benchmark along with a broadly agreed set of desired outcomes within the MDT. Cost-benefit analysis of such outcomes may also be helpful to try and justify increased resourcing.	Thank you. The framework is particularly focused on improving patient care, by encouraging shared responsibility, MDT working and a family centred approach. In the development of the framework, the working group concluded that there were certain aspects of the transition pathway that required engagement from wider healthcare, including national, regional clinical and commissioning organisations. This led to: 1. Recommendation 13 for Trusts, ODNs and Health Boards; and 2. The development of the ‘recommendations for future work’, where this was considered outside the immediate remit of the framework. ‘Exploring standards and auditable metrics to measure effective and high quality transition’ has been added to these.
	Sharon Breward Individual *(note: this comment has been included under virtually every section of this document)*	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Christine Mackerness Individual	Reference should be made to the equivalent philophies in paeds of partnership and family centred care.	Thank you for your comment. The working group thinks that this is covered in recommendations 8 and 9.
	Denise Hart	Pg 5 Communication -	Thank you for your comment.

	On behalf of National Neonatal Network Physiotherapy Leads	could it be suggested that where at all possible f2f meeting is the preference for the handover, with Parents and as many professionals as possible (not always possible but at least state desirable) this would be the gold standard for which to aim	The working group thinks that face to face handover is practically difficult for most transitions, due to the likelihood of babies needing to move hospitals or hospital sites. Face to face handover in mentioned in the Transfer of Information section regarding handover.
	Nicholas Prince Individual	All reasonable.	Thank you.
	Ryan Watkins On behalf of South Thames Paediatric Network	I appreciate the scope of the guidance is broad in terms of patient groups and sites, but I wonder if there is an opportunity to define actions we expect stakeholders to take (teams, sites, Trusts, Networks) to support the implementation of these recommendations. Currently, they feel non-specific and broad and hence risk not being measurable and not being implemented effectively.	Thank you. In the development of the framework, the working group concluded that there were certain aspects of the transition pathway that required engagement from wider healthcare, including national, regional clinical and commissioning organisations. This led to: 1. Recommendation 13 for Trusts, ODNs and Health Boards; and 2. The development of the 'recommendations for future work', where this was considered outside the immediate remit of the framework. 'Exploring standards and auditable metrics to measure effective and high quality transition' has been added to these.
	Joanne Stout On behalf of CDDFT	This section feels very linear, no mention of the work of play specialist and their role in the older neonate ready to transition to paediatrics. Nor the input of teams already consulting whilst babies are under the care of neonatologists.	Thank you. The working group thinks that the inclusion of play therapists in the 'Who makes up a team?' box in the 'Multidisciplinary teams' section should lead to the assumption that they are included in recommendation 3. Recommendation 4 is relevant to teams already consulting whilst babies are under the care of neonatologists.

	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Recommendation 1: Transfer to paediatric services should occur when care needs dictate this would benefit baby, not arbitrary age boundaries / weights. This provides a cue for discussion but cannot be the driver. Pleased to see psychology and pharmacy listed as key professionals. Recommendation 4 should go further, to highlight the need for a named general paediatrician rather than just speciality services. GP involvement is also vital. Health visiting team should be included in the MDT list. Recommendation 5: Our experience is that these families receive the best holistic care when their lead clinician is a general paediatrician rather than a sub-specialist unless there is a clear indication for this. Recommendation 6: How many trusts currently have transition coordinator. Is this realistic or aspirational? Though this is a professionals framework it will be put on BAPM website and families are likely to refer to it and therefore it may set an unrealistic expectation that could become a barrier to good collaborative working with parents believing they are not receiving the best care. Recommendation 7: MDT meetings only if necessary / add value. Not required in every situation – huge resource implications.	Thank you for your comments. The working group agrees with your comment on recommendation 1 and feel that the recommendation and the document as a whole are aligned with this. This recommendation has been changed to reflect the importance of the general paediatrician. GP and Health Visitor are acknowledged in the Process section of the framework. The framework considers transition for all babies, many of whom have a single organ issue. However, recommendation 5 has been updated to reduce the emphasis on subspecialty-specific lead roles. The section ‘Leadership and coordination of transition and ongoing care’ reflects the flexibility required to provide families with a key member of staff where services do not have capacity for a transition coordinator. The recommendation has been edited to more reflect this approach. The working group thinks that MDTs are underutilised when transitioning babies, but acknowledge that flexibility is key. The patient groups for which this framework is most relevant are those with ‘complex health and care needs’ and the working group feels that MDT meetings are a mainstay of communication for planning and executing transition.

		Recommendation 8: Whilst it is vital to work with families, and recognise their knowledge and expertise on the day to day care needs of their babies we are concerned about using the term equal partners in decision making. Whilst decision making should be collaborative, our experience is that many parents do not wish to feel the burden of responsibility of having made the decision about putting ceilings of care in place for their child but are comfortable accepting the recommendations of a clinical team that they know are making recommendations in the best interests of their child. Recommendation 9: We agree that using a trauma informed family-integrated approach is key. However family-integrated care is not universally adopted in paediatric health care settings, nor can it be currently. I worry that neonatal teams give family's an expectation and are setting them up to fail. It would be challenging to introduce FiCare into specialist services currently. Family Integrated Care (FICare) has shown significant benefits in neonatal units, but its broader implementation outside these settings faces several challenges. It is unacceptable to promote a framework of practise that is not in place and within our hospital, a failure to prepare families for this change is a cause of family dissatisfaction and ultimately complaints.	The working group thinks that this terminology is helpful in ensuring teams recognise the vital input of parents into decision-making, while allowing parents to take part to the extent they feel comfortable. The working group heard from our parent & carer panel and other parent feedback that they frequently felt excluded from discussions and care planning for their child in paediatric and critical care wards. Although the group is very aware that the FICare philosophy is not universal in these environments, it we nonetheless take the view that it is important for the benefits for babies and children from this model of care to be more widely available. Recommendation 9 has been updated to address your concerns and those expressed by others from paediatric critical care and other paediatric services. As more hospitals transition to a wide variety of electronic record systems, BadgerNet (or any other

		Recommendation 10: Is the purpose of the Badger discharge summary not to ensure standardised paperwork? If this is used universally it feels helpful to duplicate something we already have. Is there standardised transition paperwork? Further down an infant passport is also discussed. This feels increasingly complicated to the extent that it could become a barrier to handover recommendations being followed. Point 14: There is already not equity of services. BAPM frameworks mean neonatal parents are used to a completely different nursing model. This is starkly felt if they move to, for example, a paediatric ward in a specialist hospital.	system) cannot be relied upon to provide a 'one size fits all' approach. The working group do not believe that this recommendation is recommending the same nursing model for all neonatal units, paediatric critical care units and paediatric wards. The recommendation has been updated to include 'compliance with national standards'.
	Maya Parkin On behalf of Bliss	Bliss welcomes this draft framework. It is thoughtful and comprehensive, with a clear focus on family integrated care (FICare). However, there should be explicit references to health inequalities and equity of access in the introduction and/or recommendations, to align with the equity considerations (e.g. consider if families have any wider social needs) highlighted in the 'Family support' section. We recommend the addition of an equity recommendation along the lines of "Services must actively identify, record and address barriers that may limit parents' ability to be equal partners in their baby's care at admission. This includes recognising social, economic, cultural, and practical challenges and taking steps to mitigate these." Parents who can spend extended time on the unit, often those with flexible employment, financial security, proximity to the hospital, and strong support networks, are better	Thank you. Recommendation 9 has been updated to specify that families should be cared for using a 'culturally sensitive' approach. Thank you for these suggestions. A recommendation (recommendation 10) has been added along the lines you suggest. In addition, the 'Understanding the parents' perspective' subsection has been updated to recognise family barriers.

		positioned to benefit from FICare. Conversely, families facing barriers such as work commitments, caring responsibilities, travel costs, or lack of stable housing may struggle to participate fully, leading to inequitable experiences and outcomes. Units must support families with babies facing multiple disadvantages to minimise delays to discharge, as a baby's time spent on the unit is associated with parents' abilities to be present with their baby, and be able to learn caregiving skills. Recommendation 9 would benefit from the inclusion of "Families should be cared for using a culturally sensitive, trauma-informed and family-integrated (FICare) approach." The addition of 'culturally sensitive' reflects the considerations included in the 'Family Support' section of this framework. Recognition of each family's unique needs, values and preferences is critical for good psychosocial support. Similarly, robust oversight and leadership are required to tackle health inequalities. Hence, Recommendation 12 could be reworded to reflect this: "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. These processes must include leadership and oversight to ensure equity in access to specialist services and family support throughout the transition journey".	Please see above. Recommendation 13 has been updated to reflect your comments.

	Emily Goss On behalf of Babies Children's and Young People Team NHSE London Region - Spec Comm	The coordination and delivery of care section – absolutely the right thing to do but will surely be excessive for many providers so how will this be audited? Thinking of a care coordinator etc.	The section 'Leadership and coordination of transition and ongoing care' reflects the flexibility required to provide families with a key member of staff where services do not have capacity for a transition coordinator. The recommendation has been edited to more reflect this approach.
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- P5, #5: What is the most 'significant' condition? How is this decided or defined? Significant to who and to what? Physical health? Mental health? Functioning? For parents? For individual? From a medical perspective?	Thank you. This recommendation has been updated.
		- P6, #12: These pathways should include opportunities for families to visit the paediatric services they will be using before they transition and to be provided with one online space for information/virtual tours, etc.	Thank you. This recommendation is now recommendation 13 and has been updated to reflect the importance of the parent voice in oversight.
		- Information before transfer about the ward should include contact numbers so parents and families can have direct access to the new ward.	Thank you. This aspect has been added to 'Involving and preparing the family' section.
		- Additionally, acknowledging the trust families have built with staff on neonatal care whilst they often have to leave the unit and the care of their babies in the hands of the staff. Trust takes time to build up and often the transition period can be very unsettling, and families need time and space to adjust and build up trust with new staff and teams and adjust to new processes.	Thank you. The working group thinks that this aspect has been well covered in the 'Family support' section.
		- P6, #13: Staff training should ensure that staff in neonates/paeds are aware of what the others' units are like and the impact of a stay there.	Thank you. The working group thinks that this aspect is acknowledged in this recommendation for joint working and training opportunities.

	Laura Nohavicka and Christine Mott on behalf of APPM	No key recommendations about appropriately involving palliative care or being flexible around transition timing based on prognosis/EOL situations.	Thank you. Reference to palliative care has been added to recommendation 4. No other recommendations specify particular subspecialties. The working group thinks that recommendation 1 covers the flexibility of transition timing.
	Association of Paediatric Chartered Physiotherapists Neonatal Specialist Committee	point 6, 12 & 13 – we would suggest changing the language to trust or Health Board Region to make the document applicable to the rest of the UK out with England. It is also worth considering that in smaller hospital setting there is unlikely to be a transition co-ordinator as an identified role within either neonatal or paediatric service. It may be sufficient to state that each family should have a nominated person identified as a contact to support transition and outline what functions this person should serve. Assuming this person will function as an emotional and practical support helping families to develop positive relationships with the new professionals who will be caring for their baby following transition to paediatrics and differ from the "lead" consultant role? In which case, should the co-ordinator be someone from the neonatal service who knows the family well or should someone from the paediatric side of things begin to in-reach to neonates early in the transition process to begin to develop a relationship with the family and understand the care needs of the baby. Potentially the neonatal outreach nurse or an identified community children's nurse or complex care nurse could provide this function in the absence of an identified transitions co-ordinator.	Thank you. Where this is relevant in the framework, the wording has been updated. The section 'Leadership and coordination of transition and ongoing care' reflects the flexibility required to provide families with a key member of staff where services do not have capacity for a transition coordinator. The recommendation has been edited to more reflect this approach.

	Royal College of Speech and Language Therapist	Rec 3: Add in abbreviation for AHPPP in brackets	Added.
		Do numbers 4 and 5 need further reference to including AHPPPs and an MDT approach?	The working group thinks that these recommendations pertain specifically to medical leadership.
		Consider including developmental care in number 9?	Thank you. This recommendation is predominantly focused on the parent and family, rather than developmental care for the baby.
		Rec 14: Business case strategies could be mentioned to support increased funding for services where there is inequity	The working group consider this to be outside the scope of the framework, and within the remit of Trusts, ODNs and Health Boards (relevant to recommendation 15, and recommendation for future work 2).
Introduction	Fola Egbewole Individual	Transfers to a second NNU for a procedure (e.g. PDA) and transfer back to initial hospital. We know there are sometimes issues when a bed is no longer available.	Although we understand the issues, the working group does not think this pathway is relevant to this framework.
	Caroline Nyawira Individual	The introduction effectively contextualises the need for a transition framework. It highlights the increasing complexity of neonatal survivors and the emotional dimensions of transition. A stronger emphasis on longitudinal outcomes and data tracking would enhance the rationale for systemic change.	Thank you for your comment. The framework provides recommendations: - Now that 'Trusts, Neonatal and Paediatric Operational Delivery Networks (ODNs) and Health Boards...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'; and - For the future that 'Further research is required, focusing on 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.
	sally watts Individual	well presented and explained	Thank you.
	Alex Dewar Individual	As a document outlining a gold-standard approach to transition, I think that there should be a clear coupling with a need for increased resources to meet aspiration. I do not believe teams are sufficiently resourced or staffed to achieve what is set out here and my experience suggests that transition is very likely to occur in an unplanned fashion on a Friday afternoon or over a weekend in order to free up capacity, contrary to best laid plans. I think that the limitations within the current system ought to be explicit and the vision for what gold standard looks like is the aspirational leaver to try and improve funding and capacity.	Explicit reference to providing ‘information to services and regional bodies on what is required to further develop high quality transition pathways’ has been added to the introduction.
	Sharon Breward Individual	Lyndsey Hookway's PhD & Book 'Breastfeeding The Brave' has shown clearly how breastfeeding care is often just MIA - 'missing in action' in Paediatrics yet families feedback all the time how much breastfeeding means to them & their poorly child. UNICEF BFI has launched standards for Hospital Based Children's Services - these would be a useful benchmark/starting point for this document	Thank you for your comment. Breastfeeding the Brave has been included in the ‘Books, articles and texts’ section of Appendix 3, Neonatal to Paediatric Care Transition Toolkit.
	Hannah Brophy On behalf of Liverpool Women's Hospital	Timing of transition. This framework stated transition should take place around 44 weeks CGA for all babies. In surgical centres it is considered acceptable to keep babies with a surgical condition under neonatal care until 60 weeks CGA. Is this no longer the case?	Thank you. The subsection regarding timing was not intended to indicate rigidity, as suggested by the subsequent 2 subsections. There has been a number of respondents indicating similar reservations. This section has been updated to include the following.

			'It is recognised that this timeline is not appropriate for all babies and for all conditions, and flexibility will need to be exercised in many situations (see below). Nonetheless, arbitrary barriers to timely transition must be avoided.'
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	General paediatric services and GPs are key for babies and children with complex healthcare needs and should be included in the list of services who provide ongoing care.	Thank you. The working group considers that all patients will access and require the services of universal services, such as GPs. This is referred to in the 'Process of transition' 'Longer term aspects post-transition' section. We acknowledge the importance of general paediatricians with the inclusion of 'children's wards' in this list.
	Abbey Forster On behalf of Chiesi Ltd	For over 30 years, Chiesi has been a committed and trusted partner to the NHS in neonatal care. We welcome the opportunity to respond to the British Association of Perinatal Medicine's draft framework on the transition from neonatal to paediatric care for babies with long-term or complex healthcare needs. We commend the working group for their comprehensive approach and consideration across different domains and for providing a thematic approach to the key recommendations. Chiesi is a supportive partner of NHS neonatal services, offering initiatives that improve staff education, multidisciplinary standards, and the development of family integrated care practices including and beyond neonatal environments. As such, we would like to share some observations and suggestions in relation to the draft:	Thank you.

	Royal College of Speech and Language Therapist	First paragraph: Add in AHPPP services acute and community 7th paragraph: Do the two points below need examples of what they are? For example is number 2 a DGH? 2.Inpatient transition to secondary paediatric services. 3. Transition to specialist outpatient paediatric services of babies with long term healthcare needs/ medical complexity.	Thank you. The emphasis throughout the document is that where care is provided, AHPPP input should be part of that care. The working group thinks this terminology is commonly understood. Secondary services may be provided in subspecialty hospitals.
Glossary	Fola Egbewole Individual	CLD- Chronic lung Disease. Since we are talking about babies with a longer NNU stay (28 days plus) this seems like an appropriate inclusion	Thank you.
	Caroline Nyawira Individual	The glossary is comprehensive and helpful. Consider including terms related to trauma-informed care, safeguarding, and digital health to reflect evolving practice areas.	Thank you. The glossary only includes abbreviations of terms used in the text, including TiC for trauma-informed care.
	sally watts Individual	well presented and explained	Thank you
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous responses.
	Kate Renton Individual	The correct term is 'advance care planning' not advanceD.... Lose the D please :)	Thank you. This has been changed throughout the document.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Advance care plan not advanced	Thank you. This has been changed throughout the document.

Pathways from neonatal care	Caroline Nyawira Individual	The framework outlines clear pathways for transition. However, more detail on transitions in hospitals without PICU or specialist wards would be beneficial. Equity of access across regions should be addressed more explicitly.	Thank you for your comment regarding non-specialist hospitals. A number of respondents have expressed similar reservations. Amongst other changes, we have elevated 'General Paediatrics' to the top of the list of transition destinations
	sally watts Individual	well presented and explained	Thank you
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Miriam Fine-Goulden Individual	It is a comprehensive and clear document which sets out a helpful framework. It seems pretty sensible and uncontroversial except I notice the timing recommendation (on page 13): '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).' Though the framework does list 'considerations that may lead to babies remaining on NNUs beyond 44 weeks CGA', having this standard may lead to a significant increase in demand for long-stay PICU beds which may be challenging to meet and may have an impact on PICU bed capacity. Local practice will vary, but in our trust, transition typically occurs when the babies 'outgrow' the NNU ventilators, usually around 4-5kg, rather than at a specific CGA.	Thank you. The subsection regarding timing was not intended to indicate rigidity, as suggested by the subsequent 2 subsections. There has been a number of respondents indicating similar reservations. The working group is also keen to acknowledge that many impediments to transition lead to care that may not be in babies' best interests; and that respiratory support practices should not necessarily be a reason for babies not to move into paediatric services.' This section has been updated to include the following. 'It is recognised that this timeline is not appropriate for all babies and for all conditions, and flexibility will need to be exercised in many situations (see below). Nonetheless, arbitrary barriers to timely transition must be avoided.'
	Francesca Seregni Individual	To my knowledge, more and more patients have neurodisability paediatricians who are either hospital or community based. They coordinate complex care of comorbidities like epilepsy, neurodevelopmental,	Thank you for your comment. The working group agree the importance of community paediatric and neurodisability support in this vulnerable group and feel that this is reflected in the

		tone complications, dystonia, GI dystonia etc. A lot of neurodisability expertise sits in community paediatrics and with the incentives of care closer to home, these should be strengthened and I think prioritised in the guideline too.	'Longer term aspects post-transition' section and in Appendix 1 'Transition from neonatal to paediatric services: summary of MDT involvement and coordination'.
	Hannah Brophy On behalf of Liverpool Women's Hospital	-NNUs beyond 44 weeks > cardiac bypass is mentioned, unsure if we should specify other diagnoses e.g. TOF	Thank you for your comment. Cardiac bypass has been used as an example and the working group does not think that a comprehensive list of additional examples is required.
	Nicholas Prince Individual	LTV units would feature under specialist wards, but are not named directly. Absence of LTV unit puts our ICU/HDU under a lot of pressure re. infants queuing for a bed from NICU to PICU/HDU.	Thank you. Your comment is reflected in an update to the Specialist Paediatric ward paragraph.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Pg 7 – this document does include baby's on palliative care pathways. Is what is meant is not those who are at end of life? It is good to see consideration of palliative and bereavement care starting at any point in the patient journey, however Palliative Care should be recognised as a speciality in its own right alongside cardiology, gastroenterology etc. See Process of transition section for additional comments.	Thank you for this comment. 'Palliative care pathways' in the introduction has been changed to 'end of life pathways' The working group acknowledges the importance of palliative care as a medical subspecialty in its own right. We believe strongly that palliative care should be considered as providing a cross-cutting approach for babies who transition to paediatric services, where they are able to support all specialty teams where appropriate for those babies on the more complex pathways, including end of life. This formulation also mirrors that in the national Neonatal Service Specification document.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 9: - Green box - suggest changing ""NICU"" to ""Neonatal"" - Overall, I'm not convinced how well the diagram actually illustrates the pathways from neonatal care"	Thank you for your comments. Agreed and changed. EDIT

		Page 10: - Paragraph 2 - ""Figure 1 illustrates potential pathways"" - I don't see how it illustrates the point being made in this paragraph? - Just below the box it states "Figure 1 illustrates conditions" but I could not see any conditions listed in figure 1 Page 11: - Specilaist Paediatric Ward: I don't think the word "usually" is the right choice - suggest re-phrasing to "If a sub-specialist inpatient ward is available, babies with organ-specific….." - General Paediatrics: "outgrown"- I don't feel this is a helpful term here. Suggest expanding to say that these babies' have grown and/or developed to a point where their needs are better met a paediatric environment. - General paediatrics: the second sentence is oddly phrased - suggest re-wording "They require ongoing inpatient care, at a level appropriate to their needs" or similar - Home: This is a statement without a point; suggest rewording to make whatever point is being made here clear."	This sentence has been removed. This sentence has been removed. The working group agree that this sentence is unduly focused on specialist hospital pathways and has been changed. Thank you for your suggestions on this paragraph. The working group has agreed alternative wording. This sentence has been re-worded.
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- P10 (Box): Please avoid the term 'burden'. - P11 General Paediatrics: Unsure if term "outgrown" is sensitively appropriate bearing in mind a lot of babies have weight limiting conditions and weight gain/growth can be a highly emotive area for families within neonatal care.	Thank you for your comment. This sentence has been changed. Thank you for your suggestions on this paragraph. The working group has agreed alternative wording.

	Laura Nohavicka and Christine Mott on behalf of APPM	Figure 1: Having "palliative care & bereavement care" separate to the clinical teams in figure 1 perpetuates the idea that it is not a medical subspeciality that should be listed alongside cardiology/neurology etc. All these subspecialities should have input "at any time". Combining palliative & bereavement care perpetuates the idea these are synonymous without having given any explanation of the scope of palliative care separately. Also "Hospice & EOL care" are listed as a transition destination, but it should be recognised that EOL care can occur in any clinical setting and also at home, and that palliative care and EOL care are not synonymous. Page 10: Aligns palliative medicine with "genetic conditions, T18, T13" instead of referring to the broader indications in the BAPM framework, or acknowledging the majority of our work in long term complex neurodisability (which can be from pre-term birth). Page 11: Reiterates "hospice and end of life care" without linking life-limiting conditions with pre-term delivery or medical complexity	The working group acknowledges the importance of palliative care as a medical subspecialty in its own right. We feel strongly that palliative care should be considered as providing a cross-cutting approach for babies who transition to paediatric services, where they are able to support all specialty teams where appropriate for those babies on the more complex pathways, including end of life. This formulation also mirrors that in the national Neonatal Service Specification document. Your comment regarding hospice and end of life care is reflected in updated text. The working group considers that the list in this paragraph are examples, rather than indicating these are the only relevant life-limiting condition. Complex neurodisability has been added to this non-exhaustive list.
	Association of Paediatric Chartered Physiotherapists Neonatal Specialist Committee	We feel that diagram Figure 2. Page 12 is really helpful for local areas to consider how to implement a structured approach to transition especially in the absence of identified transition teams.	Thank you.
Process of transition	Fola Egbewole Individual	Can 'travel buddy' be elaborated on? Would this become an NHS adjacent role?	This refers to the role in 'Managing coordination of transition', which is now made clear in the text.

		Continuity of psychological input even when baby ihas transferred and/or equal psychological care at secondary hospital.	
	Caroline Nyawira Individual	The staged approach to transition is well-articulated. The inclusion of MDT meetings and parent involvement is commendable. Additional guidance on emergency transitions and safeguarding protocols would strengthen this section.	An 'Acute or unplanned transfer' subsection has been added to the Process section of the document.
	sally watts Individual	well presented and explained	Thank you.
	Alex Dewar Individual	3 MDT's seems excessive, they have a very high cost in terms of staff working time and therefore opportunity cost, often without objective or measurable benefit to the patient which could not be achieved with a well written clinical summary. I am sceptical of PICU becoming involved any earlier that 40 weeks corrected gestational age, NICU are firmly driving patient management before this time and so input externally will be of limited value. A cost-benefit analysis for the workload MDT's would add, along with measurable objectives and outcomes (compared with patients who do not have such meetings) may be helpful in determining the need for these either way.	Thank you for your comments. The working group thinks that the current text balances the importance and value of the MDT meeting, with flexibility for teams to decide what suits individual babies. The figure that shows 3 MDTs is not prescriptive.
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Francesca Seregni Individual	I think a model where high risk babies are known right from the beginning of the journey as they leave NICU is effective in building trust with families and addressing family expectations in terms of complications early.	Thank you.

	Jo Bennett Individual	On page 11 one of the transition destinations is listed as Home. However, in appendix 1 it is listed under Additional Considerations. Should this be the way it is referred to on page 11 too, as an additional consideration, as the majority of the framework is focusing on the hospital inpatient transition from neonates to paediatrics. On page 17 in the section Longer Term aspects post-transition, in the additional important considerations, could the last statement be 'housing, environment and access...'	Thank you for your comments. The framework explicitly includes 'Transition to specialist outpatient paediatric services of babies with long term healthcare needs/ medical complexity' as described in the introduction. The additional considerations in Appendix 1 refer to some of the services involved with babies after discharge home, rather than the destination. Thank you for this suggestion and it has been added.
	Denise Hart On behalf of National Neonatal Network Physiotherapy Leads	Pg 12 (boxes in diagram) - AHPP - should it be AHPPP? pg 16 - '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' - I think SLT and OT should be written in full rather than abbreviated here like the others are	Agreed and changed. SLT and OT are well recognised abbreviations of these professions, whereas there are no equivalently well-recognised abbreviations for physiotherapists, pharmacists or dietitians.
	Hannah Brophy On behalf of Liverpool Women's Hospital	-Process of transition/multiple meetings, great in theory however not practical if BAPM standards are not being met e.g. criteria for AHPPs to see patients are restricted, cross-site working, limited days of work etc.	Thank you for your comment. The working group thinks that the current text balances the importance and value of the MDT meeting, with flexibility for teams to decide what suits individual babies. The figure that shows 3 MDTs is not prescriptive.
	Nicholas Prince Individual	Transfer by CGA 44/40 seems undeliverable, given our NICU graduates usually have to come to our acute PICU / HDU. Bed capacity issues force these babies to queue and they are often much older. A standard may be useful, but we will struggle to deliver this. At	Thank you. The subsection regarding timing was not intended to indicate rigidity, as suggested by the subsequent 2 subsections. There has been a number of respondents indicating similar reservations. This section has been updated to include the following.

		44/40 they can often still be small and may yet be suited more closely to NICU care for a while longer?	'It is recognised that this timeline is not appropriate for all babies and for all conditions, and flexibility will need to be exercised in many situations (see below). Nonetheless, arbitrary barriers to timely transition must be avoided.'
	Ryan Watkins On behalf of South Thames Paediatric Network	May be useful to define roles and responsibilties of the named transition coordinator if the recommendation is that each infant has one	Thank you for your comment. The working group thinks that the description in the 'Managing coordination of transition' section offers sufficient flexibility for transition to be supported by staff in current roles within neonatal or paediatric services with responsibility for care coordination. It is not within the scope of the framework to provide job descriptions.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	A great deal of thought has clearly gone into considerations that both delay and encourage transition to paediatric services. We have a number of comments on some aspects of this section. 1) Pg 10 – It is not the case in all regions that ongoing care will not be handed over to a lead subspeciality. Most babies are or should be handed over to a general paediatrician and may require specialist input at some / different times in their illness journey. Sub-specialist consultants may not be best placed to co-ordinate care e.g. ENT in an airway anomaly. 2) Children with life-limiting conditions certainly require palliative care involvement, but also need wrap around care from local services (general paediatrics, community paediatrics CCNT this should be made clearer in the paragraph on page 10. 3) General paediatrics: this section does not fully reflect the role of general paediatrics in caring	Thank you for your comments. Thank you. The 'Transition destinations' subsection has been rearranged and updated to reflect the importance of pathways to general wards. The sentence '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' is intended to make your point about the most appropriate subspecialty ward. The working group has agreed a reordering and rewording of this to section of the document to reflect the involvement of general paediatric services in these babies more clearly. The pathways section is focusing on destinations rather than teams caring for the baby.

		for these medically complex babies. General paediatric teams provide a key point of contact for many of these families on discharge from paediatric services even if initially discharged to the care of a tertiary specialist service e.g. cardiology and should be involved early in the patient journey. It is good to see that the need for early general paediatric involvement is highlighted	
		4) Home: this section appears very simplistic, babies discharged home require input from multiple services such as GP, CCNT and health visitors, whilst this is mentioned towards the end of the section our experience is that the experience of patients and families is improved if these universal services are involved in care at an early stage.	The pathways section is focusing on destinations rather than teams caring for the baby. The subsequent pathways section describes the teams involved in these babies' care and discusses the role of GP etc.
		5) Pg 12 – 3 MDT meetings in unrealistic and unnecessary in many instances. Speciality consultants often do not have time allocated in job plans for these activities. This should be determined on a need basis.	The working group has updated the text to ensure it balances the importance and value of the MDT meeting, with flexibility for teams to decide what suits individual babies. The figure that shows 3 MDTs is not prescriptive.
		6) Timing – should not be an arbitrary age boundary but focus on what care the child needs. The age may be the cue to initiate discussions in one cohort of babies and thereafter clinical need should prevail. But writing the leaflet focused (as we always should be on patient care needs) would therefore also increase the audience as it could be used for babies transitioned sooner for clinical need e.g. NEC surgery	Thank you. The subsection regarding timing was not intended to indicate rigidity, as suggested by the subsequent 2 subsections. There has been a number of respondents indicating similar reservations. This section has been updated to include the following. 'It is recognised that this timeline is not appropriate for all babies and for all conditions, and flexibility will need to be exercised in many situations (see below). Nonetheless, arbitrary barriers to timely transition must be avoided.'

		7) Pg 14 – how many children's hospitals have a children with medical complexity team? We are this is alluding to services that do not exist in the majority of regions and therefore setting unrealistic expectations for families, we want this transition to succeed and, as mentioned throughout the document, it is important that families have realistic expectations of what to expect from paediatric services. 8) Pg 15 – typo 'Everyone is on the same page' 9) Pg 16 – suggesting 'earlier in the week' for transfers is unhelpful. Many specialist children's hospitals run at capacity and transfer must be based on clinical need and equitable resource use. This document needs to be pragmatic / realistic at its core. 10) Pg 17 – We feel neonatal services have a responsibility to discuss likelihood of future admissions in sickest cohort of patients. Anecdotally, families report feeling inadequately prepared for this likelihood.	The working group recognises that, although increasing numbers of specialist hospitals have such teams, they do not exist everywhere. The framework is not directive about this. A reference to the importance of a team taking a holistic overview of the baby has been added to this point. Changed. The working group does not think that this section is didactic, but rather indicates that consideration is required when transferring babies to new teams, particular if to new hospitals. Thank you. This is covered in the second bullet point in 'Longer term aspects post-transition'. 'May' has been changed to 'should'.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 12: - Both instances of AHPP need changing to AHPPP (or if one of the Ps has been omitted intentionally it will need to be specified which one - but I think full AHPPP is the correct option here) - Purple box needs space between ""parent"" and ""&"" Page 13: - Title: Considerations that may lead to a baby remaining on NNUs beyond 44 weeks CGA - but not forever. The title is open ended.	This has been changed accordingly. This has been changed accordingly. Thank you for these comments. Minor edits have been made to this section.

		- Weight and Size: ""Weight criteria may apply…"" is an exampley necessary here? I don't think it adds to the information being given, but interrupts the flow when reading, making the following part of the sentence more difficult to link to the first. - Equipment: I did eventually get what was the intended point here, but I had to re-read multiple times to figure it out. Consider re-phrasing this for clarity (perhaps AI could help?) - Do not understand why PCCs would not have respiratory equipment the right size for a term infant - Safety: Consider adding a note to say that babies transitioning in the winter months should have received their RSV immunisation shortly before transition. - If we can't transfer a baby during the winter (RSV season), that stops any transfers for 5-months a year - Availability of specialist services: Whether or not this should be included here, under equipment or as a separate point can be discussed, but we need to include a reference to the access to parenteral nutrition and specialist medicines in these considerations. Page 14: - First paragraph, bullet point #6: replace ""including"" with ""and"" when mentioning play therapists - Preparation: when do we prepare to transfer non-premature infants? Page 15:	Agree with the effect on the rest of the sentence, which has been edited. This has been changed for clarity In the experience of the working group, equipment to deliver non-invasive ventilation is not equivalent across NICUs and PICUs. Thank you. This has been added to the text under 'Safety'. This has also been updated to exercise caution, rather than advising against. Reference to parenteral nutrition added as another example. This has been changed accordingly.

		- Typo in the opening quote: ""…everyone is ON the same page."" (Currently says ONE the same page) Page 16: - Bullet point 1: """"should generally"""" is weak/vague - suggest change to ""are recommended to"" - Bullet point 7: Separate the pharmacists to a new bullet point, and phrase this recommendation like this: ""Invite specialist pharmacists from neonatal and paediatric services when the baby requires specialist medicines, parenteral nutrition or has a complex medication regime"" - Bullet point 9: change ""psycologist(s) to """"psychological professional(s)"" - Bullet point 15: Add medication details/information to this list Page 17: - Longer-term aspects, bullet 3, sub-bullet 2: ""Families may need referral to social care support"" should be a separate bullet point on its own - sub-bullet 4 - This list is introduced as important considerations; it is not necessary to repeat it for this point alone.	The working group believe that this aspect is covered over the course of this whole section. This has been changed accordingly. This wording is used to offer teams reasonable flexibility. Thank you. This has been changed accordingly. Agreed. Agreed. Agreed. Agreed.
	Maya Parkin On behalf of Bliss	Under ""considerations that may lead to babies remaining on NNUs beyond 44 weeks CGA,'' there could be a reference to babies having extended stays	Thank you for this comment. The working group considers that these aspects shouldn't delay inpatient transition as the timing is

		due to social reasons rather than purely clinical? E.g. poor housing, meaning a baby cannot easily be discharged on oxygen and delays in finding a foster placement? Bliss' Cost-of-living crisis in neonatal care report found that 2 of the 24 respondents whose babies were currently using at-home medical equipment that required electricity to run said that the rising cost of energy prices had stopped them from using the medical equipment their baby needed. This would be compounded over the winter period when electricity/heating costs are higher on average. Under ""Involving and preparing the family'' it states ''parents should be given the opportunity to visit the receiving unit..."" Could anything be said about support with arranging travel or supporting it in other ways if the unit is on a different site to the NNU?	decided by the clinical condition. We acknowledge that social circumstances may delay transition home, however, this is outwith the remit of the guideline, as it describes the transition between clinical care teams and environments. Thank you. This has been added.
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- P13 'Capacity constraints…': "…Conflicting care priorities and philosophies" sounds ominous. Might be better to write something that may be less concerning for families to read (see family quote P22). - P14: Pleased to see play specialists acknowledged. They and nursery nurses/HCAs can be fundamental with transition process and are often very experienced and family focussed. Additionally, domestics and ward clerks often provide family support in paediatrics by being familiar, consistent, non-clinical/medical staff families can relate to and who contribute towards the welcome/clean area they will be staying in for a period of time. Important to acknowledge their often-unsung role in supporting	The working group appreciates your concern. However, we feel that this is an important consideration to highlight. Thank you for your comments. The working group agrees that all staff play a role in caring for babies and families and the definition of the team in 'Who makes up a team' tries to acknowledge this. The role of the transport team is acknowledged by their presence in the MDT meeting.

		families. Transport teams also often play a very important part in supporting families moving around settings too and should be acknowledged in this document. - The health visitor- Should be involved in all aspects of transition. The HV is the constant support throughout the first 5 years. With lots of other services involved, the HV can link families with universal support, which is quite often forgotten about when you have a child with extra needs. The HV is often linked to the GP and can make sure that all immunisations are up to date. - Important to support families in talking through and setting expectations regarding FICare and accommodation as this is so different between specialities. Acknowledgement that families and babies have potentially been separated and now the expectation will be that they are always present and if not can trigger concerns. - P15, bullet 6: 'Skills' can often be a term parents do not like. Could say something like "Care/procedures that parents have been doing"?	The working group acknowledges the importance of GPs and Health Visitors as a 'crucial part of the team around the child'. Thank you. The working group thinks that the text within 'Navigating clinical and cultural differences within neonatal and paediatric settings' cover this important part transition planning. Specific reference to parental presence and accommodation and differences in parent involvement in care have been added. The term skills here has been replaced with 'activities'.
	Laura Nohavicka and Christine Mott on behalf of APPM	Figure 2: "PPC as well as specialties" - paediatric palliative medicine is a GRID speciality and should be recognised in the same terms as neurology/cardiology etc.	Thank you. This text was written to emphasise the palliative care team, whereas 'subspecialties' was shorthand for those specific specialties involved from the baby's underlying condition. The working group recognises that it may be misunderstood and have edited it accordingly. Neonatal Family Support Workers' role included.

		Page 15: "Involving and preparing the family" does not mention role of family team workers in short term follow- up contact Page 17: "Longer term post-transition considerations" does not mention the vital role of hospices in additional support which may include respite.	Thank you. Reference to hospices has been added to this section.
	Association of Paediatric Chartered Physiotherapists Neonatal Specialist Committee	"Timing", page 13. It is helpful to have a benchmark in terms of gestational maturity for when transition should occur and I think this relevant both from a skills and expertise perspective of those caring for the baby but also from an environmental perspective in terms of achieving a developmentally supportive environment.	Thank you.
	Association of British Paediatric Nurses	The draft could include clearer guidance for children's services on: • Agreed escalation pathways and rapid re-access criteria. • Out-of-hours contact arrangements with key professionals on discharge. • Roles and responsibilities for follow-up safety calls or home visits. These are essential for both family confidence and nursing decision-making posttransfer.	Although important, the working group considers that these aspects are the remit of local services and not in the scope of the framework.
	Royal College of Speech and Language Therapist	Page 12, figure 2 "parent and family input" Could this be changed to Partnering with parents and family rather than Page 14, 7th bullet point 1st paragraph Take out family-centred and keep family integrated care	Agreed. The working group has reviewed your comment and agreed to keep the current wording.

		2nd bullet point in Informing & involving teams: Involve and refer? To be clear. Consideration of involving transport teams/bed managers? Page 16, Bullet 2, 2nd sub-bullet: “Invite parents to ask questions” - needs changing to feel more partnering with families? Maybe ‘shared conversations and decision making with families’? Page 16, bullet 3 Is this true to partnering in care with families? Page 16 bullet 6 Add Psychology here Transfer & immediate approach post-transition Do PICUs have family teams or key workers that can also support transition? Should they be included here? Page 17, 2nd paragraph last bullet Needs more information. Further financial support? AHPPP services, support around work for families, more psychosocial	‘Refer to’ has been added to the text. ‘Invite parents to ask questions’ is a specific action within the MDT. It has been changed to ‘Ensure parents are empowered to ask questions’. The working group thinks that this option is an important way for teams to discuss patient care and make clinical decisions in complex situations. This bullet point is specifically about the role of AHPs in the child's ‘wider developmental needs’. ‘Managing coordination of transition’ does not stipulate from which team this coordination comes. The working group does not feel that further information is required here within the remit of the framework.
	Rachel CollumOn behalf of Family Care Team, Northern Neonatal Network	-P16, MDT meetings: Need to add something in around how individual needs of families will be supported to help them understand. EG: ESL; LDs, etc. Provide examples of potential questions/prompts and support for families if they would like to contribute to MDT discussions. Acknowledging this can feel	Thank you for your insightful comments. The framework recognises these issues and provides guidance in the ‘Identifying and meeting psychosocial needs’ in the Family support’ section.

		intimidating for families in a medical professionally heavy forum - P17: Parent competencies is a term we don’t use-see below. - Also need to highlight likely difference in support with parking, financial, food provision and the excellent use of technology to communicate with and update families eg VCreate as a lot of neonatal units provide this via charitable funds but not usually provided in paediatrics. - Also acknowledge this may be the first time their “story” is being told in a forum and can be incredibly emotional and difficult to hear/recall. Offering to have people with them “to support them” not just be present and acknowledge they may not have local family support so may need support for siblings from play specialists while these discussions are taking place.	These terms have been altered in line with your comments and those of others.
Multidisciplinary teams	Fola Egbewole Individual	Option for parents to have a follow up - during traumatic times like this, often we (parents) may not be able to ask all questions necessary (as they may not occur or we may not feel confident). option to follow up allows us to not feel as if we have missed a huge opportunity	Thank you for your comment. The working group thinks that the emphasis on ongoing communication with families with the recommendation for continuity of responsible consultant and coordination, should ensure parents have these opportunities.
	Caroline Nyawira Individual	The framework rightly emphasises the importance of MDTs. The allocation of responsible consultants and transition coordinators is a key strength. Consideration of staff wellbeing and interprofessional	Thank you. The framework emphasises team working and MDT education and learning in several places.

		training opportunities would enhance team effectiveness	
	sally watts Individual	well presented and explained	Thank you.
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Hannah Brophy On behalf of Liverpool Women's Hospital	-A number of community paeds OT teams are refusing referrals for infants, despite criteria being 0-18/19yrs -Lack of experience/competency in many OT groups in assessing and providing intervention for infants under 2yrs/ex-prems (both acute and community) despite there being evidence highlighting the challenges with function, regulation and learning/school in the future.	Thank you for your comment. Although acknowledging this may be an issue, the working group does not think that this is relevant to the framework.
	Ryan Watkins On behalf of South Thames Paediatric Network	May be useful to define importance of access to all AHP disciplines beyond neonatal care	Thank you for your comment. The working group has emphasised the importance of the MDT, including AHPPPs throughout the transition process, including in recommendations 3 and 14 and the box 'Who makes up a team?'.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Whilst there is a clear outline of recommendations for doctors and surgeons there are no recommendations for the wider MDT in this transition process.	Thank you for your comment. The working group thinks that an emphasis on responsibilities and involvement of the whole MDT is embedded throughout the document. For example, recommendations 3, 7, 10 and 14 include specific reference to MDT working and the box 'Who makes up a team' describes the MDT clearly.
	Abbey Forster On behalf of Chiesi Ltd	We recognise the increasing importance of coordinated multidisciplinary approaches to ensure safe, effective, and personalised transitions for this vulnerable patient group.	Thank you for your comments. The working group recognise your points about patchy use of electronic patient record and the potential for digital solutions to enhance the transition process.

		Chiesi has developed and delivered a plethora of educational initiatives for UK and Ireland healthcare professionals, aimed at improving the consistency and quality of neonatal care. We would value the opportunity to contribute to the interdisciplinary training described within the framework to deliver transitional care effectively. We agree with the proposal to have robust handovers and standardised documentation to support the transitional care process. As the NHS progresses its shift from analogue to digital systems, we would propose here the concept of a standardised digital ‘infant passport’. This may have the potential to reduce fragmentation and enhance continuity of care. Indeed, the analogue to digital shift offers many opportunities for neonatal units to ensure consistency of quality care. Just recently, Chiesi delivered a collaborative working project with NHS partners including a Health Innovation Network and a NHS Neonatal – Operational Delivery Network (ODN). The project, entitled Neonatology Technology Enabled Care (NTEC), was a deep dive into the current readiness and adoption of technology in the North West’s neonatal units, to identify gaps where technology could assist with driving efficiencies and consistency in care. The landscape review included 22 NWNODN neonatal units (seven neonatal intensive care units (NICUs); 12 local neonatal units (LNUs) and two special care units (SCUs)), as well as the neonatal transport service (Connect North West)	

		The subsequent report found that while some technologies, such as electronic patient records and video updates for families, are in place, their use is inconsistent. Many units still rely on outdated paper records, have patchy Wi-Fi, and lack the digital infrastructure that could make a real difference for babies and families. Our project highlights that broader transformation is required including the need for investment, sustained collaboration, and a commitment to aligning digital innovation with clinical excellence. We would also emphasise that handover and availability of documentation could be inclusive of additional care settings and extend to general practice. Awareness of the ongoing and longer-term complications of prematurity remains variable in primary care. An integrated digital solution could be supportive in addressing these gaps.	
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 19: - First paragraph: ""This may be a link nurse or AHP…."" This sentence feels unnecessary - it is implicit in the previous sentence	Thank you. The sentence is to avoid the assumption that only nurses may fulfil this role.
	Association of British Paediatric Nurses	Successful models nationally in respect of transition between children's to adult services, and neonatal services to home potentially demonstrate the value of a designated Transition Nurse/Coordinator bridging neonatal and children's services. • The ABPN recommends BAPM explicitly endorses this role as best practice.	Thank you. The working group agrees that this role is crucial. However, the framework aims to provide a recommendation around coordination that remains achievable across the range of transitions described in the document. Additionally, we feel that a model job description and competency profile is beyond the remit of the framework. The text has been edited to reflect the minimum recommendation of ABPN.

		• A model job description and competency profile could be provided to support commissioning and business case development at Trust and Network levels. This could be a hybrid of current job descriptions in respect of current neonatal transition/outreach roles and transition nursing roles in existence between children's services and adult services. As a minimum the ABPN recommends that there should be a named neonatal nurse and a named children's nurse from the receiving children's service as a key member of the planning and transition team, and for parents to know the name and contact details.	Use of the term 'key worker' indicates that these roles may be undertaken by a variety of MDT members of staff.
	Royal College of Speech and Language Therapist	Page 19, Line 3 Widen to AHPPPs? Paragraph 2 Family integrated care again here.	AHP is intended to mean therapist in this context. This sentence is not referring specifically to FICare.
	Elizabeth Brookfield on behalf of Royal College of Speech and Language Therapists	**Complex skills mix** The challenges of neonates needing ongoing support represents low incidence but highly complex cohorts, particularly in busy secondary and community settings. These are often vulnerable infants and therefore the skill mix, including the need for clinicians to be managing these infants and families in a 'trauma-informed' approach is emphasised. This highlights the need for timely supportive and active supervision and mentoring (inter / intra professionally).	Thank you. The working group recognises the challenges of staffing constraints across all services, perhaps most acutely in the community. This includes the challenges educating the workforce and providing them with skills to care for these sometimes highly complex babies. We heard this strongly from our members from all professions. This is reflected in recommendations 14 and 15 (previously 13 and 14) and 'Recommendation for the future' 5b. A more detailed analysis of staffing and education need and funding is outside the remit of the framework.

		For clinicians working in dysphagia or communication (particularly in community or under-resourced tertiary or secondary hospital settings) where this population represents a small percentage of the total caseload, they may not have access to the training, neurodevelopmental skills, and approaches that the neonatal specialist SLTs are extremely experienced in (e.g., FICare, SOFFI, Brazelton, NIDCAP, neurodevelopmental approaches). The lack of skills, confidence or competence makes not only the infants more vulnerable but also clinicians, risking working out of scope of practice, silo working, or not enabling access to local services due to lack of skill mix (emphasising health disparities and inequities). There is often limited funding for therapists to attend external training when working within the NHS. Given the breadth of skill mix needed for a whole caseload, these clinicians may also not be eligible for funding / time off to access these necessary skills or resources. The modules on NHS England education resources are referenced (Introduction to AHPs in neonatal care) but further direction on training and support for clinicians working with neonates as part of their paediatric caseload, i.e., neonates are not their sole specialism of practice, should be expanded. **Supporting neonates in community care** Point 13 (page 6): ‘Workforce skills should meet the baby’s requirements wherever care is provided…”	

		As identified in Paediatric Community Workforce Dysphagia review (RCSLT, 2023), community SLTs lack the clinical confidence, skills and training in supporting neonates in community. Neonatal ODN funded SLTs may have a remit to support neonates from 0-2 years (including neurodevelopmental surveillance), but this are often network roles or acute roles that may not adequately support the day-to-day needs of neonates as they transition into paediatric settings, especially in community settings (this would need corroborating with neonatal ODN colleagues). As highlighted in the report, joint training across neonatal and paediatrics is necessary, however, funding is needed to provide the staff and resources to support such collaboration whilst ensuring equity in delivery and funding.	
Staff Considerations	Caroline Nyawira Individual	Staffing standards and competencies are well-addressed. However, the emotional toll on staff managing complex transitions is not explicitly covered. Recommendations for reflective practice, debriefing, and psychological support should be included.	Thank you for your comments regarding staff wellbeing. Reference to this has been added into the 'Teams and teamworking' subsection.
	Bala Subramaniam Individual	Please include 'General Paediatrician' as a joint responsible physician.	This has now been included.
	sally watts Individual	well presented and explained	Thank you.

	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Hannah Brophy On behalf of Family Care Team, Northern Neonatal Network	-Inequitable AHPP services at smaller units therefore no continuation of care/no one to handover to. -Like the idea of an 'infant passport' however the practicalities around this given the current situations many Trusts find themselves in e.g. who will complete this, who will review/update it, how/where will it be stored, is it expected that the info will be at cot side, availability to translate the info (either way around – for staff and/or parents to understand). -True Trauma-Informed Care also relates to staff and feel this should be incorporated e.g. how available they are, their own mental health/wellbeing, challenging situations etc. This may support the section further down re Communication with Families and better understanding 'difficult families'.	Recommendation 14 pertains to local and regional staffing reviews, including AHPPPs. The working group was unanimous in their view that Infant Passports offer an important opportunity to provide a mechanism to enhance the family and baby's voice. The aim is for it to be co-produced with parents and owned and held by them, to use as they see fit. The working group agrees that staff wellbeing is an important consideration and has now acknowledged this at the end the 'Teamworking section.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Whilst there is not a specific section on staff considerations within the document it is clear throughout that the challenges faced by staff caring for these babies and their families has been considered. Whilst the document does reference the differences between neonatal and paediatric setting it may be useful to acknowledge the differences in staffing ratios between an NICU and general paediatric ward and the challenges this may pose for paediatric staff in terms of the expectations from parents and how this could be overcome.	Thank you for your comment. The working group acknowledges the differences in staff ratios in the various parts of the journey of babies who transition to paediatric care, including between neonatal critical care (which includes various ratios from 1:1 (intensive care, although not universally) to 1:4 (special care)), paediatric intensive care, high dependency and ward levels of care.
	Association of British Paediatric Nurses	We note that the framework outlines what should occur but lacks guidance on who is responsible for various aspects, including for example how nursing workloads are	Thank you. The working group believes that specific guidance around nursing workforce is beyond the remit of the framework. Should the ABPN produce such

		resourced or assessed, including an indication of nursing duties and responsibilities e.g. family education, complex discharge preparation, community liaison This could potentially form an annex to the current draft framework or an annex added at a later date in view of timelines.	guidance, this can be referenced and referred to in subsequent updates to the framework.
		We appreciate that BAPM has previously set out the nursing WTE and ratio for neonatal units and PCCS in respect of critical care areas for children. Relevant references for these have been included within the draft. We recommend reference to the ABPN Safe Standards with regard to children's wards which were published in December 2024 to reflect the increasing complexity of care needs on children's wards today standards_for_safe_staffing_in_children_and_young_peoples_wards_and_departments.pdf	Thank you for this reference, which is now referred to in the 'Multidisciplinary teams' section and is in the reference list.
		We are aware that the recently developed NHS England standards for neonatal qualified in speciality education outlines transition knowledge, skill and competencies from a neonatal perspective. We would recommend reference to these, as well as to outline specific knowledge, skills and competencies that the children's nursing workforce in children's services may need to acquire. For example: • Complex discharge planning • Feeding and nutrition support	Thank you for this reference. Reference to the neonatal nurse QIS competencies has been added to the 'Multidisciplinary teams' section and is in the reference list. Following discussion, the working group's view is that providing details of nursing skills and education is beyond the remit of the framework and recommends actions for the future in 'Recommendations for future work' no. 3.

		• Device management (e.g., tracheostomy, enteral feeding, home oxygen) • Family/carer teaching and assessment in recognition of skills parents have attained and are competent in being clearly documented in handover records. • Safeguarding and escalation pathways Including an outline of the above will enable children's services to plan and deliver the required education and training where required. Reference: [NHS England » National standards for neonatal qualified in specialty (QIS) education]()	
	Elizabeth Brookfield on behalf of Royal College of Speech and Language Therapists	There is a strong presumption of availability of staff across locations or that funding will solve this. This lacks clarity on the need for staff that are adequately trained and supported. Funding for neonatal services is ring-fenced and with clearly identified roles within the neonatal ODN and neonatal settings. For paediatric clinicians funding is at best piecemeal and not a single source, with posts made up of lots of different small pots of money (which may impact on cohesiveness, team contribution and clinical priorities). Neonates that transition to paediatric services therefore are included in a wider caseload and therefore, prioritised / allocated accordingly. It is important to acknowledge that neonatal and paediatric services are very different; funded differently, organised differently.	Thank you. The working group recognises the challenges of staffing constraints across all services. We heard this strongly from our members from all professions. This is reflected in recommendations 14 and 15 and 'Recommendation for the future' 5b. A more detailed analysis of staffing and education need and funding is outside the remit of the framework.

		Neonates transitioning into paediatric services (whether acute or community) remain vulnerable due to the poorly funded and vastly broad paediatric (0-19 years) caseloads with no single source of funding. Clinicians may not have the skills or experience to support such infants but rather are accommodating a wide range of children and young people across the age range with a multitude of different needs, some of which may include prematurity. Replicating or continuing the care experienced in neonatal services (due to staffing, environment, and priorities) without ring-fenced / additional funding, resources and support may not be realistic. A paediatric ward is so different from the neonatal environment – that alone can significantly impact relationships, communication and engagement.	
Family support	Fola Egbewole Individual	Working towards keeping mothers with their babies. No separation after c-section. Bed next to cot so mothers do not have to leave the hospital empty handed (it's devastating). This is a huge piece of work but acknowledging it is a step in the right direction.	Thank you.
	Caroline Nyawira Individual	The trauma-informed and family-integrated care approach is a major strength. The framework could go further in addressing the needs of diverse family structures, including LGBTQ+ families and those with disabilities. Inclusion of peer support networks and educational planning would be beneficial.	Thank you for highlighting this. The document has been updated accordingly.
	sally watts Individual	well presented and explained	Thank you.
	Kimberley Hastings	On page 20 it states;	Thank you for this comment.

	Individual	'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' This contradicts the earlier comment stating that parents are experts in their baby's care and decision making. Parents are experts in their own baby, and do not become experts by the time of transition. It therefore implies that parents are not experts until this point.	The working group has undertaken edits after a range of views were put forward during the consultation about the previous wording around parents being experts in care and other elements of parent involvement. In addition, we have endeavoured to rectify this contradiction.
	Alex Dewar Individual	I broadly agree with everything and think that this would absolutely represent gold standard care and collaboration between teams and parents and this should indeed be the aim. However, I am concerned that the report is asking for a level of input which teams are not equipped to provide. I do not believe that Paediatric units are staffed to deliver the kind of care described in this report. Wards and teams are running at close-to if not over capacity and the priority is on clinical effectiveness in an environment of scarce resources. I would recommend clear guidance on the expected minimum staffing required to achieve the status objectives. This could be used by ODN's to justify increasing the resources available to	Thank you for your comments. The working group does not believe that the framework recommendations place undue additional workload above that which all teams should be aspiring to, providing excellent care putting the child and family at the centre.

		meet the targets set out in this report by being explicit about what it would take to deliver. It is suboptimal, but I wonder if all involved would be best served by producing a document for parents outlining a realistic picture of what will be on offer once they are in a paediatric environment or how treatment approaches in PICU/HDU will differ, what the longer term for children with chronic lung disease or intestinal failure might look like - and that they learn how to adjust their expectations accordingly.	
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Frances Brooke Individual	The area I feel that has the most impact on transitioning between neonatal and paediatric care is the expectation on the family to be present for basic care needs throughout the day. The paediatric ward runs with different nurse to patient ratios and we will not infrequently see babies who are not visited for days at a time by their parent/s. This is often due to financial (travel) or childcare restrictions. Is there any scheme or financial grant that could be used to help support these families rooming in with their baby on the paediatric ward that could be outlined and identified in the early transition process?	Thank you for your comment. The working group appreciate the difficulties many families face being present when their baby is in hospital whether that is within neonatal or paediatric services. Within the constraints of a national framework there is little scope for exploring the various charitable options available to families.
	Christine Mackerness Individual	Reference should be made to the equivalent philophies in paeds of partnership and family centred care.	Thank you. The working group acknowledges that family partnership is strived for in both neonatal and paediatric services. Updates to the document emphasise this. The framework reflects that FICare has additional aspects of parent involvement that parents appreciate and value highly.

	Jo Bennett Individual	On page 25 in the paragraph Parent Competency Documentation, could competency and competence be changed to skills and assessed ability or other such phrasing. There has been a move away from using the term competency in this regard following parental feedback.	The document has been updated to move away from the use of terms such as competency and skills.
	Hannah Brophy On behalf of Liverpool Women's Hospital	-'written record of parents' skills > A national group ?Bliss did some work around this and parents didn't like the idea that they were being 'assessed'. -Neurodevelopmental f/u inequitable.	Thank you. Parents in neonatal and paediatric areas provide aspects of care that need training and services need to provide assurance in some way that parent skills have been developed.
	Anusha Arasu On behalf of King's College Hospital NHS Foundation Trust	1.Some Trusts have Paeds wards that would allow parents to stay over ? + different sibling visiting rules? - have to take into consideration varying visitation rules between NICU's and paeds wards 2. Can we have a template of Infant passport and consider standardisation of this across Trust for seamless transition	Thank you. The working group considers that this is outside the remit of the framework. The working group did not think that it was necessary to provide a template, but rather to provide an outline of the information that might go into local/regional versions of such a document.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	We recognise the anxiety that parents feel when their baby transitions from a neonatal to paediatric settings and agree that it is important that their voices are heard, particularly in terms of knowing how to comfort and soothe their child. However, as outlined in the introduction to this section, most parents are experiencing paediatric services for the first time and it is important to manage their expectations in terms of how care is delivered particularly as this may be different to their previous experience. The use of the term equitable partners is concerning as parents may feel they can expect care is delivered in a certain way,	Thank you for your comments. The working group has undertaken edits after a range of views were put forward during the consultation about the previous wording around parents being experts in care and other elements of parent involvement. The working group consisted of a wide variety of clinicians from neonatal and paediatric backgrounds. It is the working group's view that, while acknowledging that parents are not necessarily experts on their baby's underlying diagnosis, involving parents in decision-

		and this may not be the most appropriate thing for their baby. Our experience is that whilst parents are experts of their children, they are not experts on their underlying diagnosis and it is important that the expertise of the clinical teams is not undervalued. It is possible to work collaboratively with families without them feeling undervalued or not listened to, whilst maintaining the expectation that the clinical team will provide recommendations for the clinical care that each baby receives.	making for their child is a basic right and services should make accommodations for that no matter the care environment or the age of complexity of the child. It is also the working group's view that allowing parents into the healthcare team around the child enhances communication and enhances care.
		Pg 22 – what a sad reflection to read. Does it really have a place here? This serves only to berate colleagues who are working in a very different setting with a much more diverse cohort of patients in just about every respect – age, complexity, acuity. The stark difference in how services are delivered, without preparation and explanation from the neonatal team prior to transition, has ultimately led to a poor experience for all involved in this case.	The working group has thought carefully about the staff and parent quotes for the framework and feel that they fairly reflect the feedback that was provided by our staff and parent contributors. One of the quotes has had a sentence removed. Encouraging services to care for families that a way that is aligned preparing parents for transition is the responsibility of all services.
		It seems that throughout this document there is an emphasis on equitable parental involvement in care and decision-making, but this does not reflect reality. While family engagement is invaluable and should be in keeping with NICE guidance on shared decision-making, elevating families to equal decision-making status can introduce clinical, ethical, and operational risks that undermine the safety and effectiveness of NHS care. A balanced approach may better serve patients and parents. We are concerned that over-empowerment of parents in neonatal settings is contributing to	The working group does not agree that the framework advocates 'equal decision-making status' to parents. It recognises that parents and clinical teams all have the best interests of the baby at heart, that working together improves engagement and that parents should have a significant role in deciding what is best for their baby.

		increased conflict and disappointment following transition to paediatric services. Paediatric services will often feel 'less' than neonatal services – nursing ratios are less (outside of critical care) and on the wards the patient population may be more clinically demanding (given variability in age / mobility / complex medication regimes), the facilities are different (breastfeeding room / storage, provision of bedrooms) and parents may have to stay with their baby to provide care. It is a shame that this latter point is addressed only through the negative commenting of a parent. In the complex multi-specialty environment of a children's hospital it may not possible for families to get daily updates from a senior clinician in every specialty, to be involved in all ward rounds, to influence who / how / when a ward round review occurs and yet all these things can and are suggested with resultant disappointment. Parental expectation, and those of our neonatal colleagues, exceed what is practical and possible and this framework in its current form will only compound and exacerbate the problem.	Neonatal nurse to baby ratios vary from 1:4 (special care) to 1:1 (intensive care), which is similar to the variation that exists for inpatient care in paediatric services. The working group do not recognise the description in the framework of parents influencing 'who / how / when a ward round review occurs' or suggesting that they 'get daily updates from a senior clinician in every specialty'. It is also not clear why when 'parents may have to stay with their baby to provide care' it is not possible for them 'to be involved in all ward rounds'. Updates have been made to the framework to reflect concerns of respondents that the importance of family-centred care and parent involvement in paediatric services is also recognised.
	Abbey Forster On behalf of Chiesi Ltd	We welcome the draft framework's strong focus on family centred care and its commitment to ensuring that all families are recognised as equal partners in care planning during neonatal transitional care. This principle is pivotal to achieving supported and empowering experiences for parents and caregivers. Here, we wish to highlight the possibility of expanded opportunities and resources that may be valuable in supporting families through this transition. This may be through enhanced access to information and	Thank you.

		appropriately designed practical resources that extend to transitional care.	
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 20: - There is use of the words ""Family"" and ""parents"" seemingly interchangeably in this section - suggest being clearer when referring to the parents/caregivers and when referring to the wider family - ""parents are experts on their own baby"" just doesn't sound/read right - I don't disagree with the point, but think it could be phrased better. Suggest re-wording to something like ""parents know their baby best"" Page 21: - Spelling - within the text of the TiC box, change ""minimize"" to ""minimise"" Page 23: - Talking about transition: With regards to medicines, some parents may be administering medicines e.g. vitamins on neonatal unit. There needs to be discussion with the paediatric area as to whether they can facilitate this, or if not to manage parents expectations following transfer. Page 24: - Paragraph 4: add medication information and immunisation status to the list given - Discharge documentation: need to ensure red book is completed and up to date and there is clear handover of when next immunisations are required	Thank you. Please refer to the box on page 4 of the framework ‘Parents and families’. The working group has undertaken edits after a range of views were put forward during the consultation about the previous wording around parents being experts in care and other elements of parent involvement. Agreed Thank you. The working group thinks that this is covered in other areas of the framework, including the ‘Parent communication’ subsection. Thank you. Additions along these lines have been agreed.

		- Pharmacists should be able to feed into the discharge information to support any complex medicines, formulations, monitoring requirements that may need to be handed over.	
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- P19: The staff quotes whilst being used to illustrate a point could be read by families as problematic eg “challenging” family. Need clarification that they are making a point around culture. - Love the section on family support! - P25: Love the content suggested for the parent passport but please can the word ‘competency’ be avoided? Instead use “Things parents have shown they can do or “things parents have done X number of times/whilst being observed” if it needs to be more specific for regulations. - Can information get scanned onto systems once transfer has occurred? Parents often find they are able to NG feed on the NNU but then unable to on Paed ward and they need to go through another set of teaching sessions. This can make parents feel like they are not trusted on the new ward but if this information could be shared prior to transfer this would improve the flow.	Thank you. The working group has thought carefully about the staff and parent quotes for the framework and feel that they fairly reflect the feedback that was provided by our staff and parent contributors. Thank you. These terms have been altered in line with your comments and those of others. The framework acknowledges these issues and has tried to provide guidance in the ‘Parent communication and the ‘Infant Passport’’ section.
	Association of Paediatric Chartered Physiotherapists Neonatal Specialist Committee	We feel that the value of a well co-ordinated multi disciplinary approach to transition comes through strongly with family support and shared decision-making at the heart of the framework.	Thank you.
	Elizabeth Brookfield on behalf of	As highlighted on page 23, it is important to understand the family’s expectation of life in	Thank you.

	Royal College of Speech and Language Therapists	paediatric settings. Supporting and readying them for that change is essential. SLTs can support this by working collaboratively – explaining the different approaches / services. Using accessible methods such as e-resources to introduce roles / show collaboration.	
Transfer of information	Association of British Paediatric Nurses	Consistency of handover information is crucial to avoid duplication or omission. • We note that the current draft encompasses details from a medical perspective. In addition, we recommend the inclusion of a standardised nursing transition handover template, that captures key nursing data and information (clinical summary, medications, feeding plans, devices, education provided, escalation contacts). • Electronic templates should be compatible across neonatal and child electronic patient record systems. This is a critically important component that must be embedded within commissioning and service planning across networks.	Thank you. The working group agrees with the need for comprehensive handover from all staff groups, as stated in the text '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'. Reference to nursing information is now explicitly made in the 'standardised handover tools' point. Compatibility between neonatal and children's records has been added to the text.
	Elizabeth Brookfield on behalf of Royal College of Speech and Language Therapists	**Communication between teams** Introduction / handover between SLT / AHP teams where neonatal and paediatric teams differ is welcomed and great practice. Examples of this exist or have existed between acute / community services in the UK but is highly dependent on staffing / funding. Additionally, the nature of some acute and community services means clinicians share caseloads (rather than allocating a lead / sole) and so may result	Thank you. The working group agrees with your analysis. Although the balance between providing care and attending meetings is recognised, although as your response indicates, MDT meetings to ensure good handover of care and communication is crucial to families and staff.

		in instability for families in getting to know their teams. Issues with 'detailed' communication at point of discharge home to Community SLT and when this happens. Sometimes there can be reduplication of SLT input if child still known to acute setting and also referred to Community SLT this can be confusing for families. The need for timely, individualised, and regular MDTs before, at and after transition is noted. This however raises issues around funding / staffing in already over-stretched services. For example, direct clinical care and assessment may be prioritised over MDT meetings. This risks the SLT voice not being considered in the care planning which can impact on long-term care and support (noting feeding and communication can be impacted long-term by prematurity, Pagnamenta et al., 2022). There are often no follow up meetings with MDT once transferred unless requested due to concerns. Babies on transfer have acute paediatricians and community AHP and nursing services which can create communication difficulties. Some babies have acute and community paediatricians which must be complicated for families - this could be better organised. **NICU to community care** Acute to community transfer (i.e. NICU to community care) is not well documented within the draft	

		compared to within acute settings (e.g. NICU to paediatric inpatient). Generally community teams only become involved if/when needed, so they may not be involved at the point of discharge from hospital and so detailed information may not be shared. Communication between specialist children's hospital and community services is very inconsistent and we are not involved in any transfer from that hospital into community until SLT colleagues send SLT referral to request assessment/follow up. "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." – we really recognise this is a barrier for us as we are not on the same electronic patient record system. EPR and systems that are not joined up within acute and community- wider NHS Trust issue, Paperwork often delayed so may get referrals for SLT 2-3 weeks post discharge. Short notice or no notice for transfers into community, no capacity to attend transfer meetings in acute settings- often these are cancelled on the day it would be useful to provide guidance particularly with advances in communication technology around how this may be managed.	Thank you for your reflections on the particular challenges of transition of babies into the community. We have added reference to this in 'Informing and involving teams' in the Process section; and reference to discharge home has been added to 'Clinical communication' in the 'Transfer of information' section.

		If neonates are transitioned into hospital specialities that are less familiar with the SLT role (or have a poor relationship), there is a risk of not including SLTs (or other AHPs) in the on-going care or misunderstanding needs. As an example, despite careful neonatal care, some paediatric services / colleagues may be more focused on 'volume led' feeding (i.e., getting the infant orally fed and non-oral methods stopped, such as an NG tube removal) and missing the need for quality led feeding opportunities that result in long-term positive feeding outcomes.	
Recommendations for future work	Caroline Nyawira Individual	The recommendations for future work are appropriate and forward-looking. A national registry for transition outcomes, enhanced staff training, and development of MDT standards for paediatric critical care are particularly valuable.	Thank you.
	sally watts Individual	well presented and explained	Thank you.
	Alex Dewar Individual	Re. RCPCH national work - It is not clear to me what ""improve understanding between healthcare professionals"" means. Be specific in the aims and challenges rather than communicating in euphemisms.	Thank you. Many comments from respondents suggest that there is not good understanding between all neonatal and paediatric teams. Your comments on conflict between the MDT below support this. It is this that the recommendation seeks to address. Recommendation 3 has been edited in response to this and other feedback at consultation. The working group understand the financial constraints within which neonatal and paediatric services work.

		Re. Staff development - I am concerned that this will be insufficient without a concomitant increase in resourcing. There is a risk that staff will be held to unachievable standards, leaving them feeling frustrated and unsupported. There is often conflict between the MDT with regards to the ethics of resuscitating extremely premature babies who may be left with profound health needs. A running theme is that earlier or more robust palliative care involvement might be appropriate for a significant proportion of NICU babies and a sense that the NICU team are reluctant to engage with this. While I am pleased that this is mentioned at several points in the report, I think that the recommendations for future work should explicitly examine this area further. Perhaps a series of recommended, evidence informed triggers for initiating parallel planning with MDT support.	Our view is that the increasing workload referred to in the framework requires a wide response, which includes prioritising education in this complex area of children's care. Thank you. The framework has tried to highlight areas where there are issues with understanding between teams, including where there are firmly held beliefs within some teams about the care provided by others that are not based on strong evidence. Perceived reluctance to discuss end of life care or involve palliative care is specifically mentioned. The working group believes it is within the remit of the framework to improve transition, rather than explore the clinical care within either neonatal or paediatric services.
	Sharon Breward Individual	The document hardly refers to infant feeding/breastfeeding/lactation care - reference appears to be cursory - this is all I could find: Breastfeeding - as part of the Family Integrated Care (FICare) model, highlights the importance of supporting breastfeeding and providing resources for parents, such as breastfeeding support and expressing spaces. No mention of the potential need for involvement of specialist Lactation/Breastfeeding services to ensure lactation is safeguarded & breastfeeding facilitated	Thank you for your comment. Please refer to previous response.

		whenever possible. No mention UNICEF BFI care standards for Hospital Based Children's Services	
	Denise Hart On behalf of National Neonatal Network Physiotherapy Leads	In terms of the recommendations for future, they mention the need for workforce recommendations for paeds critical care. Where do we go with that in terms of who takes that forward from a physio perspective? There is the Paeds Critical Care service specification but they aren't specific about AHP staffing in the same way Neonates have been ('have access to' vs 0.5 wte/cot).	Thank you. It is not within the remit of the framework to explore or try to solve staffing issues in clinical services.
	Anusha Arasu On behalf of King's College Hospital NHS Foundation Trust	Incorporate education and training posts eg NICU grid trainee should undertake 6 months PICU post and vice versa around Transition into Paediatric and neonatal training with RCPCH , would be applicable to SPIN training	Thank you for your suggestions.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Recommendation 4 seems unclear. The general paedaitric curriculum has clear recommendations about managing patietns with medical complexity, working within MDTs and caring for acutely unwell children and neonates. Is this recommendation relating to including FICare into the curriculum? The term medical complexity does not feel well defined within these recommendations. Our experience tells us that there are many children and young people who have multiple co-morbidities, but who have relatively straightforward day to day healthcare needs, yet there are others with fewer co-morbidities with more complex needs. When making recommendations about future work it is important that we consider how we should define medical complexity within those recommendations.	The working group heard from many staff in their survey that they feel under-prepared for caring for babies and children with multi-system and complex care needs and their families, particularly at the interface between neonatal and paediatric care. The recommendations about training are a response to these concerns. Thank you for your comments.

	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 26: - 2: Is there a misunderstanding of ODNs role here? I agree that commissioners should take these actions. A separate point could (should) be made to say that ODNs should work to standardise the transition processes across their geographical area. 3: Needs re-phrasing to make the point clear. I think I understand what is trying to be said, but I am not sure. 4: add ""and"" before ""ODNs"" 4b and 4c: In general yes, these are admirable aims, but what is the link specifically to transition?	The working group believes ODNs are well placed to understand the capacity and staffing across their networks and provide essential intelligence for commissioners. Recommendation 3 in this section has been edited in response to this and other feedback at consultation. Corrected The working group heard from many staff in their survey that they feel under-prepared for caring for babies and children with multi-system and complex care needs and their families, particularly at the interface between neonatal and paediatric care. The recommendations about training are a response to these concerns.
	Laura Nohavicka and Christine Mott on behalf of APPM	Page 26: "Recommendations" - should include research into the impact of integrating palliative care into these pathways, and should include increased understanding of the role of palliative care and when a referral is timely.	Thank you. The working group thinks that the framework should not recommend prioritisation research in one subspecialty or discipline's aspect of care over others.
	Elizabeth Brookfield on behalf of Royal College of Speech and Language Therapists	**Research needs** There needs to be more emphasis on the need for robust research in this field. What happens to these vulnerable neonates and the impact of transition and outcomes across settings? The need for SLT specific research was highlighted in the RCSLT backed work on research priorities in dysphagia (Pagnamenta et al., 2022) and the ongoing dysphagia needs is emphasised by Kamity et al (2021),	Thank you. Research into longer term outcomes has been added to 'Recommendation for future work' 1a.

		which notes the impact of prematurity and feeding issues long-term and therefore has implications for the workforce beyond neonatal settings. Further research into understanding the presentation, neuro-physiology and developmental components of neonatal feeding and communication may be beneficial in transitioning neonates. Research could also consider consensus agreement on the best approach by SLTs to support these cohorts across settings and minimum training / skills requirements.	
Appendix 1: Transition from neonatal to paediatric services – summary of MDT involvement and coordination	Fola Egbewole Individual	Can we include the option of family led ward rounds? By this stage, the parents/mother often know all the babies quirks so it makes sense.	Many neonatal units offer this option to parents. The working group does not feel this is a realistic proposition in paediatric services at this time.
	Caroline Nyawira Individual	This appendix provides a useful overview of MDT roles. Future versions could include visual flowcharts and regional variations to support implementation.	Thank you.
	sally watts Individual	Clearly outlined	Thank you.
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you for your comment. Please refer to previous response.
	Kate Renton Individual	The correct term is 'advance care planning' not advanceD.... Lose the D please :) In both the cardiology and PPC sections here.	Corrected.
	Ruth Crosby-Stewart Individual	Pg 30 Community paediatric services - to include 'local sensory support service of identified hearing and/or vision needs.'	Thank you. Agreed.

		explanation - this service is a mandatory service which supports children and their families from the point of identification, regardless of age - providing there has been a referral. Some health professionals are not aware of this community paediatric support.	
	Denise Hart On behalf of National Neonatal Network Physiotherapy Leads	pg 26 onwards Appendix 1 - some professions are abbreviated, some aren't and it lacks consistency throughout the table, either need to add professional abbreviations to glossary and abbreviate all or write them all out in full pg 29 dietitian is spelt wrong	SLT and OT are well recognised abbreviations of these professions, whereas there are no equivalently well-recognised abbreviations for physiotherapists, pharmacists or dietitians. Changes have been made accordingly.
	Amy Mason Individual	Therapists are most likely the first professionals to meet the baby and family at home, not the medics. They will be the staff that parents will be asking all their questions and concerns that have come up since discharge so it is imperative that community therapists are well informed. There should be a stress on the importance of MDT communication on discharge including possible face to face/TEAMS so families can meet community staff before we enter the home. Also improved written communication of journey/condition shared with community therapists, not just community medical staff. Would also suggest that it is recommended that there is regular 2-way communication with the child's MDT from NNU specialist services throughout the neurodevelopmental surveillance process? Not always aware of upcoming specialist assessment and therefore not able to feed in to them. Emphasis on communication back from community teams working with the family regularly to feed into these term	Thank you for your comments. The working group agrees that handover of information across the whole MDT is crucial. Please refer to subsections 'Transfer and immediate approach post-transition' and 'Longer term aspects of transition', where the importance of handover of all aspects, including 'medical, nursing and AHPPPs' plans'; and the important consideration that 'community paediatric services provide multi-disciplinary support for babies with complex care needs, including extremely prematurely born babies'.

		+3/6/12 month assessments would be highly beneficial from the family so they are not having to relay this information themselves.	
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Hospice support is not referenced in the Paediatric Palliative Care section of this table, our experience is that this is a key service for this patient group. The example provided for when general paediatric services should be provided feels too limited as they are likely to be involved in the care in the majority of babies referenced earlier in the table. Children's community nursing teams should ne included in this section.	Thank you for these comments. We have taken them into account in the final version. Thank you. This has been reflected in the updated document.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 27: - Table - why are pharmacists not required for respiratory, cardiac or complex needs patients? - Additionally I think that communication from pharmacists to Primary care is really important and an area of high risk of errors - Respiratory: Suggest pharmacist involvement to organise nirsevimab before being transferred to a paediatric clinical area. Page 28: - Cardiology: Include pharmacists - may need handover of specific medicines and formulations. - Also may need to consider arranging nirsevimab if meets criteria before being transferred to paediatric clinical area."	Thank you for these comments. A number of edits have been agreed by the working group in response to these suggestions.
	Emily Goss On behalf of Babies Children's and Young People Team NHSE	LTV is also often used for patients with cardiac conditions not just lung or neuromuscular	Thank you. We have taken it into account in the final version.

	London Region - Spec Comm		
	Laura Nohavicka and Christine Mott on behalf of APPM	PPC is not listed with the other medical specialties, but separately after "other medical/surgical" as if PPC is not also a medical subspecialty. "Community paediatric services" does not list hospices as an example, and they are also not listed under PPC.	Thank you. This text has been written to emphasise the palliative care team overarching role in the transition process in some babies, whereas other the 'other medical / surgical' section is referring to those specific specialties involved from the baby's underlying condition. It is in no way meant to infer that PPC is not a medical specialty. Thank you. This has been added.
Appendix 2: MDT meeting standard agenda template	Caroline Nyawira Individual	The agenda template is practical and family-inclusive. Consider adding prompts for safeguarding, digital handover tools, and staff wellbeing check-ins.	Thank you. Attention to social aspects has been added.
	sally watts Individual	Agree with template	Thank you.
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you. This has been added in Appendix 1.
	Nicholas Prince Individual	Very useful.	Thank you.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	This feels like a very full agenda. It may not be possible to address all sections in a timely fashion and there is the potential that parents could be overwhelmed by meeting multiple new professionals on a screen. It feels important to recognise that this is not one size fits all.	Thank you. The working group has updated the text in the 'Process' section to ensure it balances the importance and value of the MDT meeting, with flexibility for teams to decide what suits individual babies. This section also does not mandate a standard agenda ie 'MDT meetings should generally follow a standardised

			agenda'. This is a template provided to assist teams only.
	Laura Nohavicka and Christine Mott on behalf of APPM	"Questions invited from teams who may not yet be part of the baby's care e.g. critical care, palliative care, children with medical complexity team and local team." It would not be normal (or best practice) for us to meet families for the first time at a large MDT, and PPC should be considered similarly to the other medical subspecialities.	The working group agrees with your comment. The text has been altered. It is important to recognise that there will be specialty teams that have been involved with the baby's care for an extended period who will have detailed knowledge of the baby; and teams that become involved as the baby approaches transition that should have the opportunity to explore the baby's story at the MDT forum.
	Royal College of Speech and Language Therapist	Questions invited from parents Should this go higher up and maybe written as "Parents ask questions of the team to find out the information they have been thinking about around the transition"	Thank you. The working group feel that this is covered in point 4, 'Encourage them to share their concerns and hopes'.
Appendix 3: Neonatal to Paediatric Care Transition Toolkit	Fola Egbewole Individual	great	Thank you.
	Caroline Nyawira Individual	The toolkit is comprehensive and adaptable. Inclusion of simulation-based training and digital dashboards would enhance its utility.	Thank you.
	sally watts Individual	Good	Thank you.
	Alex Dewar Individual	Key diagnoses - it would help to have a narrative summary for each long term condition as part of handover. In my experience paediatric services are not resourced to conduct neurodevelopmental ward rounds. If we are lucky, we may get some input from a play therapist sporadically.	Thank you for your thoughts. The working group is acutely aware of the constraints on all areas of hospital care, including neonatal and paediatric services. Appendix 3 is designed to give Trusts an outline of what their guideline or policy for transition might consider, for local teams to produce something that works for them.

		Growth - need an agreed and shared area to record this information, often EPR's used in different hospitals/areas of the hospital, do not communicate and information during the transition is lost. Screening - the Neonatal team should produce a clear timeline for screening, follow-up and vaccination progress. Social - I think that it would be helpful to have embedded social care professionals within NNU, Paediatrics and PCCU - often social care related issues become a bottleneck for transition home.	
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included in the working group & included as part of the MDT involved in care	Thank you. Appendix 3 is designed to give Trusts an outline of what their guideline or policy for transition might consider, for local teams to produce something that works for them. The feeding plan within the transition checklist refers to the Infant feeding lead. Breastfeeding the Brave and the UNICEF hospital standards have been included in the suggested resources.
	Jo Bennett Individual	In the Transition Checklist under Social information - could this also include siblings and extended family support. Learning resources on page 33, are these not learning tips rather than resources?	Thank you. Siblings and family support have been added. The Learning resources section of the toolkit includes the ‘Case example’ and the ‘Books, articles and texts’ subsections.
	Dr Jessica Macwilliam	This checklist seems to include all necessary sections. I wonder if the roles and responsibilities and parental	Thank you. Appendix 3 is designed to give Trusts an outline of what their guideline or policy for transition might consider,

	On behalf of Alder Hey Specialist Palliative Care Team	involvement sections should be separated from the practical check list of tasks above? It seems likely that the sections within the parental involvement section could be something that could be produced by each hospital/ward and provided to families rather than having to be individually written for each baby, the processes for each baby are likely to be similar for most babies; for example the way in which a ward models a culture that actively seeks out family voice and establishes parent expectation is unlikely to change for each baby who is transferred.	for local teams to produce something that works for them.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 32: - Medication summary: also include established plans or review dates for medication, and immunisation status (routine and other). Recommend this information is collated by a pharmacist where possible/available (to allow for key information around specific formulation or administration techniques to be incorprated) - Feeding plan: Include pharmacist input for any babies transitioning on PN - Immunisations: Include with or alongside medications - Pharmacists often instrumental in this information, especially with non-routine immunisations (RSV, Hep B) - Social care: Feel it is important to include this in the ""Social information"" not separately - Checklists (and everywhere else in the document), nowhere is discussed that need to ensure that ward baby is transferring to has same mediciness available to prevent any delays in treatment, especially if transferring between neonatal care in one Trust to Paediatric care in another.	Thank you for these comments. A number of edits have been agreed by the working group in response to these suggestions.

		- Also there needs to be some handover about PN especially for complex patients likely to be on bespoke."" Page 33: - 3. Learning Resources: I don't understand the inclusion of the first 3 bullet points, and their relevance to supporting learning resources - are these supposed to be here? - Bullet point 3 makes no sense - whatever point is trying to be made needs to be more clearly articulated - Case example - why not include it here, or as the next appendix - we are already in an appendix, directing to another appendix that is after others seems convoluted and unnecessary- - ""Books, articles, and texts""- couldn't it just say ""Publications""? Page 34: - Note at the end of the text - is this supposed to be on this page? It feels like an odd place to include it	This has been moved to the guidance section under heading Interprofessional Working. Thank you. The appendices have been re-ordered to move the case example adjacent to the toolkit. This sentence has been adapted and moved to the start of the toolkit.
Appendix 4: Parent Information Leaflet guidance	Caroline Nyawira Individual	The guidance is empathetic and informative. Consider adding FAQs, peer support contacts, and visual aids to improve accessibility.	Thank you for your suggestions, which have been incorporated.
	sally watts Individual	Good	Thank you
	Alex Dewar Individual	I would be extremely wary of promising anything in parent information which teams may not be able to deliver. I would focus on delivering a realistic picture	Thank you. The working group do not feel the guide is unduly didactic and should allow local services to design their own guidance.

		of what care will look like - parents will be disappointed, but at least they will not feel misled.	
	Sharon Breward Individual	Ensure Infant Feeding/Lactation Specialist is included as part of the MDT involved in care	No guidance is given on MDT members in this appendix.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	This is useful guidance.	Thank you.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 35: "Introduction" bullet points - through the framework, the term baby has been used, but now infant has been used. Suggest keeping to baby for continuity	Thank you for pointing out this oversight.
Appendix 5: Parental Transition Checklist	Fola Egbewole Individual	Include that baby may be transferred at night and highlight the pro's - less traffic, baby more settled and con's if parents are not informed or informed last minute.	Thank you for this suggestion. The working group thinks that these details can be added locally if teams this it necessary.
	Caroline Nyawira Individual	The checklist is well-structured and empowering. Inclusion of emergency planning and educational readiness would be beneficial.	Thank you. The working group thinks that emergency planning and educational readiness are already present in the checklist.
	sally watts Individual	Good	Thank you.
	Alex Dewar Individual	Mixed feelings - this somewhat infantilises parents and reads a little like something my children would be asked to do at school. It is not clear what the outcome would be if the parents answered "no" to questions like "I feel prepared to take this next step" - what are the expected interventions and actions? What if the parents never gets to "yes"? I appreciate the sentiment and the majority of the items on the list would be useful for the neonatal team to address	Thank you. The parent transition checklist has received positive feedback from respondents. It is a potential template for teams to use as they wish (or not).

		as a checklist for them, but I do not know if asking this of the parents is going to be useful.	
	Sharon Breward Individual	Ensure mother & child's needs as far as Lactation/breastfeeding/ infant feeding are included	The working group thinks that this is covered by ‘I am supported and experienced in feeding my baby’.
	Nicholas Prince Individual	very useful	Thank you.
	Anusha Arasu On behalf of King's College Hospital NHS Foundation Trust	- My feelings about the transition are being heard and respected. - I know it is normal to feel excited, scared, and everything in between. These don't feel like a "checklist" item - it should avail to be more qualitative information	Thank you. The parent transition checklist has received positive feedback from respondents. It is a potential template for teams to use as they wish (or not).
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	Agree this could be adapted by local teams if they feel it would be helpful.	Thank you.
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- P32: It’s really important to coproduce this checklist with families to ensure the tone/content is right for them. - P36: Parent checklist needs to be health literacy friendly. Could this be developed further in collaboration with parents? Some of the wording feels a bit patronising.	Thank you. BAPM has a parent and carer panel appointed for this framework reviewing this guideline and will update the checklist if feedback suggests it.
	Laura Nohavicka and Christine Mott on behalf of APPM	Transition checklist should include advance care planning.	Thank you. As most babies who transition to paediatric services do not have palliative care input or advance care plans, this should be discussed on an individual basis rather than be included in a generic checklist.

Appendix 6: Case example of a high-quality transition	Caroline Nyawira Individual	The case example is illustrative. Future versions could include diverse scenarios and highlight best practices in digital handover and safeguarding.	Thank you.
	sally watts Individual	Helpful	Thank you.
	Alex Dewar Individual	It is not clear which outcome measures are being impacted.	Thank you. The case study is included to be illustrative of what good therapist involvement looks like, particularly as the working group is aware of the variability of provision across the country.
	Sharon Breward Individual	Ensure mother & child's needs as far as Lactation/breastfeeding/ infant feeding are included - what should good/high quality Lactation/breastfeeding/ infant feeding care look like - what does breastfeeding 'support' mean? Including the UNICEF BFI care standards for Hospital Based Children's Services would be a good starting point	Infant feeding support information increased in the framework in response to feedback. This case example focuses specifically on AHPPP input.
	Hannah Brophy On behalf of Liverpool Women's Hospital	Appendix 6 – case study with AHPPP involvement – not an accurate representation of OT, need to consider the variability between OT nationally.	This case study was developed with Occupational Therapy input, although the working group appreciate that, as with most areas of neonatal and paediatric staffing, there is wide variability across the country.
	Anusha Arasu On behalf of King's College Hospital NHS Foundation Trust	should be HNNE not HHNE in the physio venn diagram	Thank you. This has been changed.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	This feels very busy. I am not sure how much it adds to the document in its current format.	Thank you. The case study is included to be illustrative of what good therapist involvement looks like, particularly as the working group is aware of the variability of provision across the country.
	Christian Chadwick On behalf of NPPG Neonatology SIG	Page 37: - ""-Anna"" (need to remove the accidental -)	Thank you. This has been changed.

		- Clarify if 5-year old sister is sister of Liam or Anna (reads as if Anna's sister, but suspect actually is Liam's sister, Anna's daugter) Pharmacist additions: - Advice on administration of medicines via NJ tubes - Discussion and education of Anna re: medicines throughout admission, with additional input for discharge - ongoing supplies in the community, ancillaries, where to go for help. - Supporting monitoring and optimisation of medication regime (e.g. MBD bloods and treatment adjustments, electrolyte disturbance monitoring and management from diuretics)"	Thank you. Text has been updated to reflect these suggestions.
	Royal College of Speech and Language Therapist	Suggested reordering/wording Support for suck feeding /breast feeding and early communication development Protect from the development of persistent feeding difficulties including aversion	Thank you. This has been changed.
Any other comments	Fola Egbewole Individual	Views of a mother of a baby born at 26 weeks, who spent 15 months in five NNU's across London. Happy to participate more *(phone number was provided – will share if requested by group)*	Thank you for your valuable insights.
	Caroline Nyawira Individual	No. thank you for looking into this area	Thank you.
	sally watts Individual	Overall a very clear, detailed and comprehensive document. Will be very useful if implemented by clinical services and teams	Thank you.
	Amitava Sur On behalf of EAST LANCASHIRE HOSPITAL NHS TRUST	Thanks for a very comprehensive and much needed document. My comments pertain to the process of transition and appendix 1. It is indeed ideal that for the preterm infant with s-BPD in requirement for LTV assessment	Thank you for this insight. The 'Informing and involving teams' subsection of 'Process of transition' now has an additional bullet point regarding MDT support prior to transition.

		the process of transition and MDT discussion should start from 36 weeks, but in reality it is aspirational due to regional bed constraints. Hence a large portion of such infants continue receiving care in neonatal unit well beyond 44 weeks, which is often stressful and suboptimal. Should there be some directive/ narrative around: 1. How tertiary specialist teams can remotely support this process through some form of hub and spoke approach 2. How ODNs can support this through virtual MDT forums where complex cases can be discussed and triaged for transition - will need job planning and specialist commitment 3. How local teams can develop complex care approach to adopt a holistic overview of such infants beyond routine ward rounds These I believe are important aspects around the actual transition process	
	Caroline Powell Individual	*dietitian spelling error on page 29*	This has been rectified throughout the document
	Shu-Ling Chuang Individual	I was looking forward to this guideline, hoping it would offer some impetus for improving the transition of neonates beyond 44 weeks or with complex needs into more appropriate paediatric care settings. Unfortunately, it's disappointing to see that it largely reiterates existing knowledge without addressing the real challenges around paediatric capability and preparedness to manage neonatal graduates.	The working group thank you for reviewing the guideline. The volume and thoughtfulness of respondents' comments suggest that yours is not a universally held view.
	Benjamin Lakin	Thank you for sharing the BAPM Transition document for review. We would like to share our feedback and	Thank you.

	On behalf of PICU Consultants, Alder Hey Children's Hospital	concerns. This is an extensive document and is an important piece of work to prepare families of neonatal patients for transition. We do however, have significant concerns about this document.	
		1. We strongly advocate that the premise of transition should be centred on clinical benefit, rather than commissioning arrangements or arbitrary age cut-offs. Clinical care must always be guided by the best interests of the patient. We recommend that the framework explicitly states this principle, ensuring that transition decisions are not influenced by non-clinical factors. This approach is consistent with paediatric services' practice of providing care based on expertise rather than fixed age boundaries.	The working group strongly agrees with this, and believe it is reflected in the first recommendation 'Care should be provided in the right place at the right time'. 'Clinical condition' has been added to the first sentence of this recommendation. In addition, text has been added to the 'Timing' section to further reflect the need for flexibility. The working group also consider that 'postnatal age, size and developmental stage' are important factors in deciding where care is best provided.
		2. Where a patient is being transitioned to Paediatric Critical Care, we believe it is essential for a Critical Care Consultant to be actively involved in the process. Given the complexity of care required for post-neonatal patients, the involvement of consultants with relevant expertise should be formalised within the framework, perhaps through the standardised MDT agenda. In our experience, there is a considerable cohort of patients who require critical care at a later stage due to predisposing post-neonatal factors, such as a history of 'mild' respiratory disease. The impact of these factors has often been underestimated or inadequately communicated in both neonatal and respiratory paediatric practice. An MDT approach will help	Thank you. The guideline stipulates in the subsection 'Informing and involving teams' that 'Critical care teams will need to be involved in transition discussions for babies requiring or likely to require high dependency or intensive care'. However, as the introduction describes, although babies who have been born preterm constitute a significant proportion of PICU admissions, a very small proportion of babies who are born preterm require PICU admission. The framework aims to provide recommendations that do not unduly burden clinicians

		ensure continuity of care and recognition of the unique skills required to manage these patients is identified from the outset.	with involvement in transition processes, when there is a low likelihood of future involvement in care.
		3. We note the framework's strong endorsement of the neonatal model of family-centred care. While we support the principles of family involvement, we wish to emphasise that paediatric services also deliver high-quality, family-centred care, albeit through different approaches. The document should acknowledge that both models have merit and that differences in practice do not equate to inferior care. As with transitions to adult services, it is important to prepare families for changes in care models and to communicate these differences openly and respectfully, rather than assert that care should be different for neonatal graduates. This document abjectly fails to communicate or even acknowledge this fact.	Thank you. The working group acknowledges that family partnership is strived for in both neonatal and paediatric services. Updates have been made to the framework in several areas to reflect concerns of respondents that the importance of family-centred care and parent involvement in paediatric services is also recognised. The framework reflects that FICare has additional aspects of parent involvement that parents appreciate and value highly.
		4. We are concerned that some of the quotes included in the document are inflammatory, one-sided, and may inadvertently undermine trust in Paediatric services. We recommend that all feedback and quotations be reviewed for balance and sensitivity, ensuring that both positive and negative experiences are represented fairly. We have many examples of families who are very satisfied with the care they receive and are indeed glad to have transitioned to a service that can provide for babies' ongoing medical needs under one roof. The framework itself stresses the importance of respectful	The working group has thought carefully about the staff and parent quotes for the framework and thinks that they fairly reflect the feedback that was provided by our staff and parent contributors. Potentially polarising/inflammatory comments have been removed, whilst remaining true to the parental input provided. Encouraging services to care for families in a

		communication and collaboration, which these quotes undermine. We hope that these very carefully considered comments are helpful Regards Dr Ben Lakin, Consultant Paediatric Intensivist, Alder Hey Children's Hospital on behalf of PICU Consultant (Drs Marie Horan, Sarah Mahoney, Anand Wagh, Carla Thomas, Darren Gates, Ikhlas Ahmed, Adil Dingankar, Simon Davies, Kha Nguyen, Petr Jirasek and Chinmay Joshi)	way that is aligned and preparing parents for transition is the responsibility of all services. Thank you for your constructive comments.
	Stephen Hancock Individual	This is an excellent document. I think it could be more prescriptive on the need for advanced care planning for babies with a significant burden of chronic illness and poor prognosis.	Thank you.
	Alex Dewar Individual	Fix funding and supply, ration appropriately, set realistic expectations - I am concerned that teams will be unable to deliver on this standard and will be left feeling frustrated and unsupported. Ensure that the pathway is deemed aspirational coupled with an explicit recommendation for what resources will be needed to achieve it to aid commissioning and to support teams.	Thank you. The framework aims to provide a balance of achievable recommendations, with aspirations for best practice and suggestions for oversight and audit. The working group's view is that details of specific resources and suggestions for funding arrangements are outside the scope of the document.

		Prioritise key outcome measures that the gold standard pathway is designed to support and audit results.	
	Sharon Breward Individual	This document appears to badly need some 'benchmarking' for breastfeeding/lactation/infant feeding care - first of all it needs to be explicitly 'there' in same way as other areas of care are included, secondly the specialist BF/Lactation/IF team needs to included as part of the wider MDT & 3rdly minimum care standards of the UNICEF framework need to references as an expected service level care standards framework	Thank you for your comment. Please refer to previous responses.
	Jon McViety Individual	I'm slightly disappointed not to see significant general paediatrician or community paediatrician input to the working group for this document. I completely understand the need for a framework of transition for children with complex speciality healthcare issues or on-going critical care needs. The rationale for transfer from a neonatal unit to a general paediatric bed is often less clear. The infant ""out-growing"" the neonatal unit is a less strong in clinical mandate for transfer in isolation. General paediatric wards operate very differently to neonatal units. Parents are expected to be resident most of the time and undertake most of the routine cares for their children e.g. dressing, changing, bathing etc. On a neonatal unit parents generally go home at night. This can sometimes create friction between nursing staff and families. Babies graduating from the neonatal unit often have a profile of problems associated with their stay on the	Thank you for your comments. The application process for working group membership was open to all paediatricians and the working group included a general paediatrician with an interest in neonatal care, who was able to bring their expertise to discussions about transition into general paediatrics. The framework has been updated in several areas to strengthen the general paediatric aspects of the transition pathways. Thank you. The working group agrees with the challenges inherent in the differences between neonatal and paediatric environments and has tried to be clear about these and offered potential solutions throughout the framework; and strengthened these in response to the consultation.

		neonatal unit this is less familiar territory for paediatricians who may no longer have a neonatal workload. E.g. minor electrolyte abnormalities, metabolic bone disease, need for specific prem formulas etc.... We find locally that on-going in-reach for any such babies from neonatal colleagues to the paeds ward is helping in managing these minor issues. Exposure to respiratory viruses and other infections on a general paediatric ward is a significant concern and I'm pleased to see that mentioned in the document as one of the reasons transfer might be delayed / avoided in the winter.	Thank you for this insight. This has been reflected in an update in ‘Transfer and immediate approach to transition’. Thank you.
	Miriam Fine-Goulden Individual	Very helpful piece of work - thank you.	Thank you.
	richard Nicholl Individual	I think it is very detailed and well thought and written. I think that in some of our complex neonatal patients they are ""too old"" for special care (ie >44 weeks CGA) but not appropriate for busy children's ward (babies with RSV and teenagers with mental health issues who should not be there). We perhaps need an alternative to special care vs childrens ward for some of these ""graduates"" who are not yet ready for home. The ""lead"" Consultant: when there are multiple co-morbidities (eg short gut plus epilepsy plus other). Who should be the ""lead"" and what happens when the lead is away? Tricky. Community services: these are variable and patchy. We have 3 different community services all with their	Thank you for your interesting insights. The working group has suggested an approach to this challenging issue, and suggests this important issue involves explicit MDT discussion on a case-by-case basis.

		own ""rules"" about who they will see and when (and what if any, investigations will organise). There needs to be consistency. CAHMS: this service grossly underfunded and understaffed leading to very long waiting lists. lastly (appreciate not remit this document) palliative care needs to be fully funded, not a charity, and part of the NHS	
	Jo Bennett Individual	This is a really written and comprehensive document which is very much needed to support the transition process for families and staff. The flow charts and appendices add valuable support to the overall content of the framework.	Thank you.
	Denise Hart On behalf of National Neonatal Network Physiotherapy Leads	Overall the feedback has been positive and it was thought that the document was thorough and well thought out.	Thank you.
	Hannah Brophy On behalf of Liverpool Women's Hospital	Overall, the document reads well. However the practical aspects need some consideration otherwise it will become just another document that units are striving to meet/adhere to, whilst not acknowledging just how much pressure units are under and the financial cuts that are being made.	Thank you. The working group agrees that simply writing a framework will not make transition better for children, families or staff. There will need to be a concerted effort from the paediatric community to drive change.
	Nicholas Prince Individual	The challenge for PICU/HDU will be delivering on the age / weight criteria. We currently have a queue and it is getting longer. Interventions such as tracheostomy need ethical framework discussions.	Thank you. The working group agrees that the challenges of capacity are acute across neonatal and children's services.
	Anusha Arasu	1.Recommendations for future work : point 4 b and c seem to be greyed out in the draft ? reason	This has been rectified.

	On behalf of King's College Hospital NHS Foundation Trust	2. General recommendations for which resuscitation algorithm is appropriate depending on age on NICU 3. Given equipment and staff specialty training, are there any recommendations about ""hardstops"" for transitions given the contsraints of resources eg bed capacity and if the neonatal and paediatric networks would support transfer to other units	The working group considers that this is outside the remit of the framework. The working group considers that operationalising the framework is the job of Trusts, Networks and Health Boards.
	Amy Mason Individual	An excellent and very helpful document.	Thank you.
	Clare Chamberlain-Parr On behalf of PICU Psychology service at Alder Hey	It is acknowledged that direct NICU > PICU transfers represent less than 1% of the transitions from neonatal services to paediatrics. The application of the recommendations in the draft document may be harder to apply for this small percentage of babies so whilst the framework is helpful, it feels necessary to tailor its application to this specific population / the clinical environments. For example, transfer of parental competencies does not translate for direct NICU to PICU transfers and it would be helpful to clarify that, under these circumstances, parents are often not able to continue with all aspects of the direct care. However, this does not mean that these skills go unacknowledged or lost, rather that parents need to be supported to adjust how they are involved in their baby’s care in this new clinical environment. The language used around parent’s expertise / knowledge of their baby is not always sensitive to parent’s needs. For many direct NICU > PICU transfers, their baby has just arrived – often	The data provided in the introduction are that <1% of babies admitted to neonatal units transition as inpatients to PICU, not that <1% of inpatient transitions are to PICU. The remit of the framework and the working group was to provide guidance on the pathways set out in the aims. It acknowledges the differences in transition journeys that are dependent on destination. The working group thinks that artificial barriers to parent participation in care across services should be acknowledged and mitigated. However, the framework has acknowledged these differences and recommended in the framework that these differences are explained to parents. The working group has undertaken edits after a range of views were put forward during the consultation

		unexpectedly and in traumatic circumstances. For these parents, the narrative that they ‘know their baby best’ can be less helpful, placing expectations on them and creating a sense of failure as a parent and, ultimately, contributing to a sense of disconnection. It would be helpful for this to be acknowledged in the document, allowing for a recognition that getting to know your baby is a process, that there are a range of factors that can make this harder to do when your baby is poorly and that the PICU team are able to support you in the first stage of this journey. Expectations re the extent of MDT preparation and involvement may not always align with the reality of urgent NICU > PICU transfers (e.g. meeting families / touring PICU). The time required to facilitate a number of MDT meetings (with parents present), introductions or visits prior to baby’s arrival is not afforded to these situations which are often time critical. The guidelines around how MDT’s work in this specific context need to be operationalised if they are to be useful for direct NICU > PICU transfer of care. It would feel helpful to have an ‘acute’ transfer process articulated alongside a ‘planned’ transfer process.	about the previous wording around parents being experts in care and other elements of parent involvement. Thank you. The working group has listened to feedback about emergency transfers and a section ‘Acute or unplanned transfer’ has been added to the framework.
	Joanne Stout On behalf of CDDFT	Needs further work overall including genaral and community paediatricians and nurses.	Please refer to previous feedback.
	Dr Jessica Macwilliam On behalf of Alder Hey Specialist Palliative Care Team	The universal adoption of FICare in paediatrics and/or the NHS as a whole is unrealistic due to: 1. Environmental and Infrastructure Limitations Neonatal units are often specially designed to accommodate parents, with space and facilities that support their constant presence. In general paediatric	The working group has listened to feedback on this subject and has updated the framework to consider this. Please refer to previous responses. The working group has extensive experience of neonatal and paediatric inpatient settings and note

		wards, space constraints, lack of privacy, and clinical setups not conducive to family involvement make FICare harder to implement. 2. Cultural and Institutional Barriers Neonatal care has embraced a culture of parental partnership, but other specialties operate under more traditional, clinician-led models. Some components of FiCare we should strive for across all settings however universal adoption and therefore using the same 'branding' is not. 3. Complexity of Patient Conditions In neonatal care, the focus is often on a single patient (the infant), with parents as primary caregivers. In multi-patient settings, the complexity of conditions and treatments may limit the feasibility of involving families in direct care roles. 4. Emotional and Psychological Factors Parents in neonatal units often have a strong motivation to be involved due to the vulnerability of their newborns. In other settings, family members may face emotional stress, lack of confidence, or logistical barriers (e.g., work, travel) that reduce their ability to participate consistently. Families need to be prepared for this change e.g. staying with their child and providing their cares for most of the time during an admission to a general paediatric ward. Pg 24 – documentation. Much of this is duplication from earlier in document Pg 25 –How many centres are reliably using infant passports to facilitate transition? Do they represent more paperwork that may end up not being read, due	that the positive and negative aspects of environments for parents and families that you mention are widely shared. The working group and the parent and carer panel are acutely aware of the cultural and institutional barriers to a culture of parent partnership. Notwithstanding the updated wording referred to elsewhere, the working group feel that the framework has a role in promoting a shared culture across neonatal and paediatric settings. The framework has focused on the transition of babies, particularly those with complex healthcare issues. The working group and parent panel consider that the experiences, challenges and motivations of parents are the same wherever their baby is cared for. The framework has been updated to strengthen the acknowledgement of the barriers to parent involvement the guidance for preparing parents for changes they might experience. Thank you. The working group has tried to reduce duplication as far as possible.

		to the volume of documents recommended which in turn will cause upset for families?	The working group was unanimous in their view that Infant Passports offer an important opportunity to provide a mechanism to enhance the family and baby's voice. The aim is for it to be co-produced with parents and owned and held by them, to use as they see fit.
	Abbey Forster On behalf of Chiesi Ltd	At Chiesi, we offer our support to BAPM in the ambition to drive better connected care and would be delighted to discuss any opportunities to work together where there is a recognised shared goal. It is well recognised that industry partners can help achieve shared goals and ambitions to improve outcomes for patients. The Association British Pharmaceutical Industry (ABPI) have a range of reports highlighting that working together can help achieve much more than working in silos. This includes a publication released at NHS Confed in 2024, entitled accelerating transformation – how to develop effective NHS industry partnerships, available from https://www.abpi.org.uk/publications/accelerating-transformation-how-to-develop-effective-nhs-industry-partnerships/ The Kings Fund, NHS and Life Sciences industry partnerships, 2024, also have produced reports highlighting the benefit of working together to help support outcomes for patients, this is available online from https://assets.kingsfund.org.uk/f/256914/x/a53a8f5edb/lifesciencesnhs_report_full.pdf.	Thank you.

		We are highly supportive of this framework and look forward to reading the final publication.	
	Christian Chadwick On behalf of NPPG Neonatology SIG	General comments: 1. Overall there is a lot of excellent content included in the framework, however this is not communicated in the most effective way. There is a lack of structure, organisation and flow to the framework which has resulted in significant repetition of information, a difficulty in following the processes being recommended, a lack of clarity in my mind of the actions to take, and it makes the document very difficult to read. There are multiple instances I will endeavour to highlight in the specific page-by-page comments where I cannot elicit the point being made from the text that is written. 2. Throughout the document there is the use of ""children with medical complexity team"" in a way that implies this is a standard term for teams that exist. These teams do not exist everywhere, and where they do will not have this standard name. A more general description and and acknowledgement that this type of service is not universally available would be more accurate 3. Repeated mention of surveys to MDT staff and to parents, 2 points: - I do not recall, nor can I find any communications about this survey. I am not convinced that this was sent to neonatal or paediatric pharmacists, and if so, it is not truly representative of the whole MDT. Were all other professionals invited to respond?	The working group acknowledge that this is a complex area and appreciate your detailed and helpful input. Acknowledgement of these teams being referred to in various ways has been added to the document in ‘Pathways from neonatal care’. The surveys were administered by the working group and were circulated widely. However, it is likely that some staff groups were not surveyed.

		- Both surveys are acknowledged as being unpublished. Shouldn't they be published so that they can be referenced properly in the framework? It is like saying, ""We have evidence for the recommendations we are making, but we're not going to tell you what it is"" 4. It is very wordy 5. I am very disappointed about the lack of detail of pharmacist involvement in the transfer of these patients. I often think that if a pharmacist was consulted at some point in the journey, then medication errors/delays/risk would be significantly reduced.	At time of writing the results are unpublished, although the staff survey was a poster at the BAPM Annual Conference and a presentation at the PCCS Annual Conference. The plan is for results of both surveys to be published. Thank you to NPPG for engaging with the consultation and the working group are pleased to have their input.
	Emily Goss On behalf of Babies Children's and Young People Team NHSE London Region - Spec Comm	- Trusts and ODN collaborating – this would involve both neonatal and paediatric ODN so should be explicitly stated - reference to any process or plans if there is refusal to take from neonates to paediatrics…we know this happens so where it references transition destinations should there be something about how to manage refusal or a recommendation that is incorporated into existing trust policies? - the concept of 'outgrown' the NNU needs an effort at defining. What are the conditions, milestones and reference guides on what this might best look like (age & gestation probably not the best markers). - The lists on page 13 and 14 are very helpful and I wonder if this could form the basis of a scoring system that predicts and guides decision making around the right time to transition.	Recommendation 13 has been updated to state this. It is already stated in recommendation for future work 4. Reference to arbitrary barriers has been added to the 'Timing' subsection of 'Process'. The term 'outgrown' has been removed. There is no validated scoring system that the working group is aware of, although your suggestion is an interesting one. Interdependent and conflicting

		- Ideal world within a trust the MDT co-ordinate the ongoing progress and care delivery to a defined end point regardless of which unit they are on, this may reduce some resistance to step down and improve cross departmental working. - Predicted impact on neonatal and PICU utilisation and occupancy - Opportunity to improve the pathway for medical complexity, this also has links to UCP although note the reference to an infant passport mentioned later in the document -Pinch points with some units and specialty expertise? - Neonatal / community outreach variability will have a likely impact	priorities in babies with complex healthcare needs will make this challenging. Some members of the MDT will deliver care across neonatal and paediatric services (mostly AHPs and paediatric surgical and some paediatric medical subspecialists). However, the configuration of services is such that core medical and nursing teams will be different across neonatal units and paediatric services in most situations where complex care is delivered. Flow from neonatal to PICUs will improve NICU capacity and may impact on PICUs. Onward flow to HDU, LTV units, inpatient paediatric services and the community is a consideration. The working group acknowledges the challenges of capacity across the system. Specialist resources will vary across units as will the availability of community teams.
	Rachel Collum On behalf of Family Care Team, Northern Neonatal Network	- Twins/multiples not mentioned at all within the document. We have met a parent of multiples who had all 3 children in different settings at one point and found it incredibly challenging trying to be in 3 different places. We know multiples have a high chance of spending time in neonatal care and often require ongoing medical support. Also, ensuring multiples are able to spend time together if separated. This parent highlighted the difficulty with access arrangements for her additional twin and older sibling to be on a paediatric respiratory unit due to strict IPCC regulations. She was breast feeding them and they were all incredibly young so needed their mother equally. Often neonatal families requiring	Reference to the challenges of multiple pregnancies and separation has been included in ‘Family support’. Reference to the need to consider the needs of siblings is also mentioned in this section.

		specialist paediatric care are out of area so don't necessarily have family support nearby. Siblings needs to be addressed and included in care too as lack of support can have a lifelong impact upon their wellbeing and ability for a family to function beyond hospital. - Also, little acknowledgement of breastfeeding/expressing breast milk throughout the document. Support varies from neonatal settings who often have dedicated feeding leads to a unit with no/little feeding support which can be very difficult to navigate especially as it is likely to not have been an easy journey and feeding and nutrition is incredibly important for the growth, development and emotional wellbeing of these families. - How will expressing work on the paeds ward? What facilities are available? Often NNUs will loan out breast pumps while admitted to NNU but these may need to be returned on discharge. Again, this is something that maybe the HV could support with. IE: Does the community have a facility that loans out breast pumps? Do they have facilities to sterilise on the ward, what does this look like and how does it differ?	Thank you. Additional references to infant feeding support have been added. The working group acknowledges the challenges of the neonatal and paediatric ward environments across NHS estates, in particular where expressing and breastfeeding are concerned. Specifics for finding solutions for this are outside the scope of the framework.
	Laura Nohavicka and Christine Mott on behalf of APPM	In general, the document does not integrate palliative care into ongoing ward-based or intensive care-based management where there is prognostic uncertainty, and seems to consider it an alternative pathway aligned with bereavement and end of life care. ACP is incorrectly attributed to being short for "advanced care plan" instead of "advance care plan",	Please see previous comments regarding the updates to the framework in relation to palliative care. This error has been rectified.

		and is attributed in appendix 1 to cardiology, "other medical/surgical" and PPC, rather than to neonatal service/PICU services or (more correctly) the team with established rapport and knowledge of therapies that may or may not be provided. There is no definition in this document for "life-limiting" or "advance care planning". There are some typographical errors such as "at a least" and "everyone is one the same page", and quotes in boxes are not always attributed as to whose perspective they represent. We would be happy to endorse this framework if our requested changes are considered and a final draft is sent for confirmation of endorsement. We would be happy to provide definitions of advance care plans and LLC if this would be helpful. Likewise, we would be happy to provide a paragraph about the scope of paediatric palliative care if this would be helpful.	The framework references the 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine, a BAPM Framework for Practice', rather than repeat aspects of that excellent document. Thank you. Any typographical errors have been rectified. Thank you for your offer. The working group has agreed that it is not necessary, in the context of this framework and the availability of other guidelines and frameworks around paediatric palliative care, to provide definitions within this document.
	Association of British Paediatric Nurses	The ABPN strongly supports BAPM's intention to improve safety, consistency, and family-centred care for infants transitioning from neonatal services to children's services. The framework provides an essential foundation for national standardisation and reflects shared priorities across professional groups. However, from a children's nursing perspective, we believe the current draft would benefit from greater operational clarity and linkage to for example current data sets and commissioning documents—	Thank you. Thank you. The working group has discussed your points and feel that providing granular detail on these matters is beyond the remit of this document.

		particularly around nursing workforce planning, defined competencies, escalation processes, and measurable quality indicators. These elements are vital for consistent, safe, and sustainable implementation in clinical Practice	
		The ABPN recognises the draft framework's strengths in: • Prioritising continuity of care for infants with complex or long-term needs. • Promoting multidisciplinary and family-centred collaboration. • Highlighting system-level coordination between neonatal, children's, and community services.	Thank you, we appreciate the importance of these points.
		We recognise that BAPM like the Association of British Paediatric Nurses is a UK wide professional organisation. We have noted that the terminology used predominantly relates to England systems and structures. We would recommend reviewing to ensure that terms, structures and commissioning/service planning in devolved nations is also encompassed.	Reference to Health Boards has been added.
		We would also recommend that consistency is required, with other terminology i.e. children's wards, children's high dependency and children's critical care being referred to rather than paediatric wards, paediatric high dependency and paediatric critical care.	This has been reviewed and amended.

		Many organisations have already changed signage to terms using ‘children’ rather than ‘paediatric’ – and children’s hospitals referred to rather than ‘paediatric hospitals’. Having reviewed the current draft as the UK professional body representing children’s nurses including those working within neonatal units across the UK, we believe the document could be strengthened. If it is not possible to cover all areas we have identified below if the publication timeline does not allow, perhaps supplementary annexes could be added at a later date or an explicit mention made in the section regarding further work required. We would welcome the opportunity to assist in such an endeavour to enhance the pivotal nursing contribution and nursing roles have to a successful transition for neonates, parents and family.	Thank you. The working group understands that there will need to be further work on these issues and have included ‘recommendations for future work’ to recognise this.
		It may be worthwhile considering inclusion of a mention of the contribution of Local Authorities ‘early help’ and public health support from health visiting services, as well as voluntary and charities such as Rainbows Children’s Trust Charity who can offer additional wrap around support for the family, including siblings.	An update in the Family Support section considers these services.
		The framework could be enhanced by identifying additional metrics to assess success, that could be recommended to be added to the current minimum	Thank you for these suggestions.

		neonatal dataset to monitor transition quality and parental experience. This could for example include: • % of transitions from neonatal services to children's services with completed standard handover documentation • % of families demonstrating competency sign-off as appropriate prior to transfer • 30-day unplanned readmission rate following discharge from children's services to home • Parent/carer satisfaction score • Time from transition decision to completed handover and transfer to children's services Such metrics would support benchmarking and continuous improvement across Networks.	The framework is particularly focused on improving patient care, by encouraging shared responsibility, MDT working and a family centred approach. In the development of the framework, the working group concluded that there were certain aspects of the transition pathway that required engagement from wider healthcare, including national, regional clinical and commissioning organisations. This led to: 1. Recommendation 13 for Trusts, ODNs and Health Boards; and 2. The development of the 'recommendations for future work', where this was considered outside the immediate remit of the framework. 'Exploring standards and auditable metrics to measure effective and high quality transition' has been added to these.
		Equity and Network Consistency Without clear expectations, variation in transition nursing coordination, care and support may persist across regions of the UK. The ABPN recommends that BAPM require Network-level Transition Agreements specifying minimum standards to ensure equitable access to appropriately skilled nursing staff within children's services.	Thank you for this suggestion. The working group thinks that requiring Network-level Transition Agreements is outside the scope of the framework. Recommendation 13-15 are written to encourage such approaches between services and regions.
		Conclusion The ABPN commends BAPM's leadership in addressing the transition gap between neonatal and children's services. Nurses play a pivotal role in coordinating care,	Thank you. The working group recognises the crucial role played by all nurses in safe and effective transfer of babies from neonatal to paediatric services. BAPM will reach out to ABPN for further updates. The framework has referred to the guidance you have recommended.

		supporting families, and ensuring safe continuity during this critical period. We believe the framework could be strengthened by embedding explicit nursing workforce, competency, and quality assurance guidance and links as highlighted above. The ABPN is willing to assist and collaborate in ongoing and further work to ensure that aspects we have highlighted are addressed.	We expect BAPM to work with you and other stakeholders on any work that comes out of this framework in the future.
	Royal College of Speech and Language Therapist	In some sections where processes are detailed, e.g. 'multidisciplinary meetings', they should include a bullet point that states - ensuring interpreters present where required, following local interpreter guidelines (i.e. not family members). Also inclusion of safeguarding and social services involvement in transition.	Thank you, this has been included. Thank you, this has been included.
	Lynda Velhurst, King's PICU	Paediatric outreach to unit units when there is a waiting time for a bed. Respiratory MDT/ LTV teams supporting Direct Transition Home from NICUs A little bit more about ethical dilemmas and NICU and Pediatric services working together with families to find a resolution.	Thank you, a point along these lines has been included in 'Informing and involving teams'. Thank you, specialist team support for discharge has been added to 'Pathways from neonatal care'. Additional reference has been made to the ethical frameworks available to help teams explore these aspects.

	Elizabeth Brookfield on behalf of Royal College of Speech and Language Therapists	**Resources for SLTs** Our members suggested that the following resources would be helpful for SLTs.	Thank you. Some of these references are included in the framework. We recommend the RCSLT reach out to members with this information.
	Maya Asir, BAPM EDI Steering Group	Suggestion to adjust the disclaimer paragraph from "the framework **uses** the terms woman and mother" to "the framework **may use** the terms…", this framework is a good example of what that doesn't use refer to mother / women. And there is a paragraph under the disclaimer about families, not sure why it's in a box? Could follow nicely from the disclaimer paragraph under the language header.	Thank you. This has been changed. The working group decided to specifically have a separate box for our definition of 'parents and families', as we refer to these extensively throughout the framework. It is used as a definition, rather than a disclaimer.