British Association of Perinatal Medicine

Consultation Response Form

Document Title: **Safe and Effective Repatriation of Infants to Care Locations Closer to Home after Specialist Care**
Closing date: **19/04/2023**
Please return this form to: **bapm@rcpch.ac.uk**

Comments received on this form will be shared with the BAPM working group to assist with the production of a final version of the document. We will publish the comments received with names attributed on the BAPM website alongside the final published document. Please note that due to the large number of comments received during consultations for BAPM publications we may not be able to respond to all comments on an individual basis.

Jo Adams (Bleasdale), Advanced Paediatric Physiotherapist, Yorkshire and Humber Neonatal ODN joanne.bleasdale@nhs.net

Page number/ heading / general comments	Line number/ 'general' for comments	Comments Please insert each new comment in a new row.	Response LWL/SN (27/04/2023)
AHP section (Page 13, bullet point 2)	Bullet point 2	I think this document needs to recognise that at present due to lack of AHP staffing a baby may not be able to see an AHP once transferred to a lower-level unit. Parents need to be aware of this and know if concerns are raised that a community referral is made by the receiving unit to ensure that parents remain supported by the right people. Infact if therapists have been involved on the level 3 unit, then a referral onwards to community services should be made regardless if a receiving unit has no support.	*Agree with your comment. Relevant text modified to include this aspect*

Sarah Davidson, Neonatal Consultant, SONeT Wessex Lead, University Hospital Southampton Sarah.Davidson@uhs.nhs.uk

Summarising comments received from the Neonatal National Transport Group meeting on the 23/03/2023 although individuals may have also submitted comments.

Page number/ heading / general comments	Line number/ 'general' for comments	Comments Please insert each new comment in a new row.	
9	Capacity transfers	A frequent request to the national transport teams is to change a planned repatriation to an emergency capacity transfer to expedite the transfer and create a bed. Parental feedback stated that ideally repatriations should not become emergencies to allow for parents to be present etc. These requests cause huge difficulties for teams in prioritisation of repatriations and may impact on other patient journeys. Capacity transfers should be discouraged and will be triaged by the transport teams – acute uplift in care transfers will always take priority	*Framework group (page 17) recognises this issue and have mentioned clearly in that framework that capacity transfers should follow locally agreed escalation pathways.*
10	48 hour time frame	Regarding the comment that the transfer should take place within 48 hours. The NTG felt that it was important that the 48hours should starts when the transport team have received a referral, triaged and deemed the patient fit to be transferred AND a bed is available at the receiving hospital. The clock needs to be "restarted" if beds became unavailable after initial acceptance -this is a frequent issue with organising repatriation.	*This document is a framework that provides broad recommendations on effective repatriation. 48-hour time frame is there is enable appropriate discussion and escalation to facilitate timely repatriation. This should not be seen as measure of transport team responsiveness but a means to achieve effective repatriation.*

Sarah Edwards, Lead Care Coordinator, Thames Valley & Wessex Neonatal ODN sarah.edwards@nhs.net

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Title page	The title of the framework	Title is very long – use of words 'specialist care' in this sentence could imply that the unit families are moving to are not specialist (all NNUs are specialist units to care for neonates)	*Changed to 'SAFE AND EFFECTIVE REPATRIATION OF INFANTS"*
P5	Point 3	Needs a comma inserted after word 'process'	*Document amended to reflect comments, flow chart updated. Thank you.*
P5	Point 5	Phrase 'back transfer' could be replaced by 'repatriation' to keep language consistent	
P7	Flowchart – 'pathway' section	Additional arrow needed from box "check repatriation threshold of local unit" to box "Senior nurse to check cot availability…."	
P7	Flowchart – 'parental involvement' section	Last box "Give information on local unit…." Should swap places with the middle box "Parents are given…."	
P8	2nd paragraph	Words 'patient flows' could be swapped to 'pathways' as easier to understand. Last sentence (starting 'Regionalisation of neonatal care…') is a clumsy sentence that could be rephrased to make it easier to understand.	
P12	2nd bullet point of 'universal support' section	Words 'step-down of intensity' should be changed to 'reduction of intensity'. This is because parents have commented on the concept of a 'stepdown in care' when the are repatriated to a local unit – this has left them less confident in their local units, and language has not been helpful.	

Cath Harrison, Transport Consultant and Clinical Lead, Embrace cath.harrison@nhs.net

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Page 7 Repatriation Flow chart	Green boxes	This isn't representative of our regional model, we are the 4th busiest, of 16, Neonatal Transport Service in England & Wales. It suggests that the senior nurse checks the bed availability, and requests transfer. This may work for single NICU regions or in other areas, however we serve 4 NICUs and 13 LNUs/SCUs and multiple NICU to NICU repatriations. Also, the flow chart doesn't link non-acceptance with that box but with thresholds set – which is counter intuitive to the statement later in the document about discussion around those babies near or below birth thresholds.	*Framework suggests best practice, local customisation is appropriate where needed. Flow chart amended to reflect your suggestion, thank you*
page 11	NICUs	Consider a repatriation liaison/link role This role in our region is currently partly fulfilled by Embrace, the local transport service. It feels like we would have multiple people trying to feed into a system, where previously only one channel has been, successfully and efficiently employed.	*This is to 'consider' NOT a 'must do' recommendation. If you have a system that already works for you, you should continue with that.*
page 15	Audit interactions	This statement is very loose and not very 'SMART.' What standard do you want to use to audit against? The actual audit standards are missing. Does the working group envisage leaving that up to each ODN to decide, or is the vision for a national audit? Is there any funding that will come with this kind of work? Would the expectation be for the Transport service to do this work or ODNs. Would the results of any Audit activity have any effect on resources, as one of the greatest barriers to repatriation is not actual cot availability but nursing staff numbers.	*These audit metrics are broadly listed in the roles and responsibilities section. It is up to the provider unit or ODN to decide on which metric(s) are to be audited and how frequently these audits should be undertaken.*
Page 17 (outside normal pathways) seems to contradict page 17 (criteria for	Responsibility for out of area repatriations	The statement on page 17 is correct: Criteria for transport service • Where a patient is to be transferred across commissioning or network borders the responsibility for the transfer lies first of all with the team covering the infant's booking hospital of delivery (as per service specification)	*Change local team to 'home network'*

transport service)		As opposed to the incorrect statement on page 18: “Repatriation outside normal pathways Out of area repatriations There may be situations where following an unexpected delivery in a network outside the family's geographical network, a planned admission for specialist treatment or capacity, or family re-location requires a repatriation across network boundaries. The following should be considered: • Network to monitor out of area activity. • Responsibility of transport of these infants sits with the local team” Also it would be useful to clarify “local team” - do you mean local transport team, or do you mean local neonatal unit team?	
Appendix 2		See appendix 2 and 4 – in an age where we are trying to cut down on unnecessary paperwork, this seems like duplication and could be better done on Badgernet, and therefore shared with other units.	*These are examples of good practice and currently BadgerNet is not configured exactly to do this. These forms can be electronically completed and shared.*
Appendix 4		Appendix 4 repat communication log feels onerous and duplication from Badgernet. We would predict it would not be filled in thoroughly. In our region the Transport team are the go-between for units. This prevents duplication, unnecessary and multiple phone calls. We recognise that not all transport services work in this role, but this supports our regional units. We work in a region where nursing vacancies are high, and are working hard to address this retention and recruitment issue.	

Kelly Harvey, Senior Lead Nurse and Advanced Neonatal Nurse Practitioner, North West Neonatal ODN

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P7		Useful flow chart on P7 but doesn't match the criteria on P16. This looks like local criteria from an ODN rather than what is in the service spec. The SS does state some units have pathways for SCUs to take babies 30+0 to 31+6 but only if there is a pathway in place & BW over 1000g. As you know this isn't part of the spec for FGH and probably other SCUs across the country.	*Flow chart amended*
P11		HRG2 & 3 (why not HRG 4 & 5 as they definitely shouldn't be in NICUs). Some HRG4s can be with parents but not quite ready for home so could repat back to a local unit. HRG5s are minimal and should have gone home.	*Included HRG 4 (XA04Z), HRG 5 is normal care which shouldn't be for prolonged periods.*
P11		Whilst it is an option to enter on Badger if baby was in-booked this field is not always completed so there will be gaps in the data or guesses made based on post code. If this data is going to be included in the guidance it ideally needs to become a compulsory field on the Badger admission.	*Agree, will approach BadgerNet to do this, but cannot be guaranteed that will happen*
Section Roles & Responsibility		Network Reasons for delays to the clinical readiness to repatriate (including clinical factors, staffing and other infrastructure issues, availability of specialist AHP and Psychology services at the receiving unit to support ongoing care). • Monitor/Audit defaults or exception on above metrics' *We feel the monitoring of this data needs to be clear – who will do this and what will it include – is it the responsibility of the local AHP service or the network. Could there be an example resource to ensure there is some correlation in what we collect nationally?*	*It is up to the ODN to decide if and how they will monitor this. Framework can only make a broad recommendation. We understand ODN resources may vary*
Communication	Page 14	There is no reference in this section regarding the difficult conversation to be held within AHP services where there is no AHP team in repatriation unit – the emphasis of this document is open & transparent communication so there needs to be some reference in this sentence regarding the 'challenging' conversation that have to be had where services being used and seen as	*Page 14 communication with families* *If a specialist AHP service is not available in the receiving unit, parents should be informed about this well ahead of repatriation and ongoing plans to be made to support the receiving unit in any ways possible.*

		needed for an infant are not available in the receiving unit to support the family in understanding this and avoid this adding to the anxiety about the new team.	
Guiding Principles	Page 15	It should be acknowledged that the benefits of a networked approach for repatriation may result in infants moving to care settings that are unable to offer a full range of AHP and psychological services/support. Innovative models of support could be considered e.g., virtual MDTs, ward rounds etc to extend a level of support however there should be appreciation that not all centres can offer ongoing MDT support (including AHPs) due to capacity and current funding I have significant concerns regarding the examples suggested here – to make any recommendation in change of management the baby will have to be clinically assessed – the danger of the suggested is that recommendations are made without clinical assessment – this also requires time to come out of other funded services hence masking the workforce issues. This should be clear that this is a system wide issue regarding appropriate funding not a clinical issue where one unit is not as good as another which is the potential interpretation – suggesting virtual MDT etc does not feel sustainable or appropriate when this is not common practice and likely to be across different organisations where governance does not exist to support clinical management for an individual professional.	*Framework is acknowledging this gap and asking units to consider virtual models of care. Framework is not suggesting to make clinical assessments virtually.*
General		Great involvement of psychology and recognising the impact on families of this part of a neonatal journey and the impact it has	*Thank you for your kind words*

Rachel Lomax, Advanced Neonatal Nurse Practitioner, Manchester University NHS Foundation Trust Rachel.Lomax@mft.nhs.uk

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7	Page 17	The weight specific guidance in the flow chart does not match that in the table on page 17	*Flow chart amended to match Repatriation Criteria in page 16*
16		Corrected gestation for multiples is one day less than for singletons for repatriation to a SCU – is this correct?	*Page 16 change 31+6 for SCU multiple pregnancies to 32 weeks*

Evonne Low, Neonatal Consultant, Imperial College Healthcare NHS Trust e.low@nhs.net

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General	Entire draft	The word infants, babies and patients are used interchangeably throughout the draft. Was this intentional? I am used to using only 1 term (be it infants, babies or neonates) to be consistent throughout the paper.	*Framework group aware of this. Terms used contextually. e.g. 'You're feeling scared if your **baby** will be ok in the new unit', **infant** won't flow well in this context*
General	Entire draft	The page numbers were centralized until page 5, before they were on the right bottom corner. For consistency, could this be rectified?	*Pagination standardized, thank you*
General	Entire draft	Should the words meant to be abbreviated, be abbreviated when they are mentioned first on the draft? For e.g., MDT, AHP, LMNS. Or add a page for abbreviations.	*Glossary of terms included*
General	Entire draft	The space between the preceding word and numerical citations [1,2] are sometimes absent, sometimes present. For consistency, could this be rectified?	*Amended, thank you*
7	Point 4	… **are** essential	
7	Flow chart	The flow chart is missing some full stops, such that it reads incongruously.	
7	Flow chart	**≥**27**+0**, **≥**30+0-32**+6** w. Abbreviation here GA and CGA first introduced.	
7	Flow chart	Give information **to** local unit	
7	Flow chart	**Give** parents opportunity	
8		.. benefits of **safe and** effective repatriation	
8		Regionalisation of neonatal care into defined geographical areas or networks, ~~has~~ unquestionably improved outcomes [1,2] for infants who required intensive care, but this ~~has~~ resulted in the need for infants to be transported between services in a network, to ~~for~~ uplift ~~of care in~~ utero or ex-utero care.	

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8		There are 10 established Neonatal Operational Delivery Networks (ODN) ~~established and~~ functioning within England, with ~~and~~ similar existing arrangements ~~exist~~ across Northern Ireland, Scotland and Wales.	Amended, thank you
8		in England ~~.~~ (NHSE E08Sa) [3].	
8		Published evidence on repatriation is limited, ~~and~~ mainly from non-UK settings and of an observational nature. These studies ~~have~~ shown that repatriation is safe, cost effective and decreases total length of stay [4,5]. (missing full stop here) Unpublished data collected, as part of a repatriation QIP(spell it out, only used once in draft) in an English LMNS (abbreviation first introduced, spell it out), showed 14.6 days of care further away from home than necessary in a randomly selected cohort of 13 babies born < 27 weeks.	
9		framework but because of its association/relevance will be briefly addressed in S~~s~~ection 5.5.	
9		Returning to ~~the~~ home service following; specialist opinion, investigation, treatment, procedure (e.g. surgery/cardiac/ROP), or clinical review.	
9		The choice of booking hospital for maternity services is open and families may choose to book at ~~a~~ maternity units outside their local catchment area.	
9		These high-level principles aim to ensure an individualised care approach for each infant, to support the right level of care in the right clinical setting for on-going care needs.	
10		A trauma -informed approach	
10		(FiCare, Discharge Planning etc), AHPs, Practitioner Psychologist and parents.	
10		Repatriation, and neonatal transfer in ~~more~~ general~~ly~~, can be a significant source of distress for families.	
10		Resisting re-traumatising families in ~~the~~ ways ~~that~~ repatriation is approached.	

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10		Safety:. Families feel that their baby is in a safe environment.	
10		Empowerment, voice and choice for families.	*Amended, thank you*
10		Additional information about trauma informed approaches in neonatal care and during perinatal period can be found in Sanders and Hall	
11		~~In order to~~To ensure ~~that~~ the principles of effective repatriation are enacted, definitive individual roles and responsibilities are needed ~~to be identified~~.	*Amended, thank you. Definitive not needed in group's view*
11		Reasons for delays to ~~the~~ clinical readiness to repatriate (including clinical factors, staffing, ~~and other~~ infrastructure issues, availability of specialist AHP and Psychology services at the receiving unit to support ongoing care).	
11		Monitor/a~~A~~udit defaults or exception on above metrics.	
11		Facilitate shared learning across the network to improve safe and effective repatriation.	
11		Referring ~~U~~unit to activate Patient Referrals function in BadgerNet settings, ~~in order for~~to enable ~~the~~ receiving unit ~~to be able~~ to view ~~the~~ patient record for any babies who have not previously been in their unit, but are to be repatriated ~~to~~ from the referring unit. (See Appendix 2, Sections 1-3).	
11		Ensure the "~~p~~Patient ready for transfer" box is~~to~~ checked on ~~d~~Discharge details section in~~of~~ BadgerNet (Appendix 2, Section 4).	
11		These should be reported using HRG2016 levels of care which refer to HRG2 as XA02Z; and HRG3 as XA03Z.	*Amended, thank you*
12		Adhere to Network Guideline.	
12		Develop and maintain a process to monitor ~~any~~ infants transferred in- or ex-utero from your service.	
12		liaison/link role. (see sample	
12		Agree on a process for organising repatriations that is easy for teams to navigate and delivers timely transfers.	
12		ICB (spell this out as used once only in draft)	
12		to provide capacity for safe and effective repatriation.	
12		F~~or those f~~amilies ~~who~~ experiencing~~e~~ more worry or concern about repatriation, or for whom there are additional psychosocial risk factors (e.g., limited network of support in friends and family), targeted support should be offered to minimise the impact of ~~the~~ repatriation transition.	
13		Appendix 3 outlines a framework for ~~that can inform~~ collaborative dialogue with a family to identify targeted support needs.	

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13	~~For families who are reluctant to~~To engage reluctant families in a repatriation plan, Appendix 4 ~~also~~ offers suggestions on ~~for~~ how conversations can be approached to understand their reluctance.	
13	Families ~~may have been~~ receiving additional support from psychological professionals during their baby's admission prior to repatriation~~. In such cases,~~, should conduct a joint~~ed up approach should be taken with~~ collaborative handover of support from the NICU or LNU to their home unit.	Current wording flows better (framework group view)
13	Where the provision of psychological support in the home unit is not equivalent to that in the NICU or LNU, units could arrange an agreement to allow a brief, time-limited period of continuity from the NICU or LNU psychological support service during the transition. The purpose of this continuity ~~would be~~is to ensure there ~~is~~ a safe ending to any ongoing intervention, and to signpost families to alternative sources of support.	Amended, thank you
13	If ~~infants are~~ under the care of an AHP ~~there~~ should ~~be a process~~put in place a process to ensure an active referral is made for ongoing care with counterparts in the receiving unit if this service is available.	Current wording flows better (framework group view)
14	underpins safe and effective repatriation	Amended, thank you
14	empowering parents' voices and choices	Amended, thank you
14	When repatriation is anticipated, families should be given the opportunity for regular updates by ~~with~~ the clinical team to support them in~~to~~ understanding their baby's progress ~~of their baby~~, providing further parental reassurance ~~. This is with the aim of supporting parents to appreciate~~ that the repatriation plan is clinically safe for their baby. Such support is of particular importance for families whose babies~~y~~ had~~s~~ been acutely unwell or required ~~especially~~ intensive levels of care prior to repatriation.	Current wording flows better (framework group view)

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14		EveryAll units should have details and virtual tours available to families on their websites, which should be linked to, through central network websites.	*Amended, thank you*
14		a key aspect of a safe andn effective repatriation	
15		Where there is a delay or complex requirements, consultant to consultant communication should take place.	
15		A process to audit these interactions, with an aiming to improve communication should be in place.	*Current wording is better (Group's view)*
15		The Patient Record Referral function within Badgernet (see Appendix 2) patient record referral function should be utilised. This allows the receiving local a unit to view read- only record offor any infant that is within their catchment area, whobut is currently within another unit.	*Amended, thank you*
15		recognising their clinical needs,	
15		Any exceptions to this should be agreed at network level, with and agreements clearly documented and agreed with Specialist Commissioning and LMNS.	
15		There should be a clear on-going management plan of the infant's care needs before repatriation, including, where necessary ; ongoing input from specialist teams (see Section 5.4).	*Current wording better (Framework group members view)*
15		Innovative models of support could be considered, for e.g., virtual MDTs, ward rounds etc, to extend a level of support. Hhowever, there should be an appreciation that not all centres can offer ongoing MDT support (including AHPs) due to capacity and current funding issues.	*Amended, thank you*
16		Corrected gestation ([singleton)], ([multiple)]	*Amended, thank you*
16		TCVC e.g., Broviac or	*Amended, thank you*
16		Cranial MRI following cooling	*MRI in this context could only mean cranial or brain MRI, current wording retained*
16		Some infants may have complex care needs, beyond over and above that encountered byin extreme preterm or a sick term infant, for e.g., post-surgical infants, need for complex ongoing interventions (ventricular drainage), long- term parenteral nutrition, tracheostomy care, etc.	*Amended, thank you*
16		Repatriation decision for these infants should not be just criteria- based, but include all relevant stakeholders (including local paediatric service for infants	

		≥> 44+0 weeks corrected gestation).	
17		requires ~~a~~ repatriation across network boundaries.	
17		Principles of communication to be continued and ~~to be~~ observed.	
17		Capacity/staffing or extraordinary incidents related to infant movements, should follow locally agreed escalation pathways.	
17		escalation plans.	
17		Antenatal counselling of women in local services prior to IUT (spell it out, as only used once) should be an opportunity to explain pathways of neonatal care, including back transfer of care ~~back~~ to ~~the~~ local neonatal service when this is appropriate.	
17		Women booked for delivery with onsite NICU services, under the care of fetal medicine / maternal medicine, ~~should be~~ ~~counselled~~ their antenatal~~ly~~ counselling should include ~~to~~ explaination of neonatal care pathways ~~of care~~ within the n~~N~~etwork, including back transfer of care ~~back~~ to local neonatal services.	*Current wording retained.*
17		Additionally in antenatal classes ~~,~~ ~~where~~ women, ~~have~~ booked for maternity care away from their local unit, ~~they~~ should be informed about neonatal network care pathways ~~of care~~, including back transfer of care ~~back~~ to local neonatal services, as soon as possible, after the identification of their babies'~~y's~~ potential or actual requirement for neonatal critical care.	*Current wording retained.*
17		~~transferring~~ referring unit	*Amended, thank you*

22		Once populated, this information will be available to ~~for~~ receiving unit on unit reports tab under 'cot availability' report.	*Amended, thank you*
23		What are the factors that may~~ight~~ make repatriation more challenging for a particular family? This may~~ight~~ include experiences of trauma, practical considerations, or differences in understanding.	
23		What strengths, resources and skills does a particular family have, which will help them navigate the repatriation process? This may~~ight~~ include a support network, or ways of managing distress that are working well.	
24		Taking time during an admission to understand how family members may~~ight~~ express distress, will help identify when and what type of support is best offered, ~~both around the~~regarding repatriation process and more generally.	
24		Understanding a family's preferences for the offered support ~~they are offered,~~ and their relationship with help, more generally ~~,~~ will guide the clinical team towards offering support which is sensitive and attuned to a family's needs when difficulties arise.	*Current wording retained*
24		There are many possible reasons why ~~that~~ families may be reluctant for their	*Amended, thank you.*

		babies to be repatriated to a local unit.	
24		There may be practical considerations ~~that mean~~why the current unit is preferable; historic trauma or problematic experiences of care in the home unit~~ or hospital~~ may make repatriation feel threatening for parents. T~~; or~~ traumatic experiences during a baby's current admission may~~ight~~ make it harder for a family to feel that repatriation to a lower intensity of care is a safe plan.	
24		Approach with the attitude of "What matters to you?", and not "What is the matter with you?" More information on this approach can be found at ~~here:~~ https://www.whatmatterstoyou.scot/	
25		Clicking on "Repatriation information video" shows some hotel video.	
25		Clicking on "Repatriation Information poster", generates a document in codes that do not make any sense to me. Scanning items need to be reviewed again in detail.	*QR codes checked by multiple members of the group and appear to be working fine*
25		Repatriation Communication Proforma (NICUs & LNU/SCUs): both profomas showed **missing colons** where they are supposed to be.	*Non-material, aesthetic change. Document serves the intended purpose colons missing or not*

Angela Marsh, Consultant Clinical Psychologist, Yorkshire & Humber Neonatal ODN

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	General	This is a very impressive consideration of the application of TIC with helpful operational guidance attached to it.	*Thank you for your kind words*
Pg 14 and Pg 18		I think reference 10 should be 11 Kazak – re: stepped care	*Amended, thank you.*

Andrea Mayes, Advanced Neonatal Nurse Practitioner, Royal United Hospitals Bath andrea.mayes@nhs.net

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15		There is nothing in there about timing of repats ie. In terms of day/night time and the impact of this on families and lower level units. I think this is hugely important, as LNU and SC teams have less staff at night, and accepting in babies is harder, plus it's hard on the families to have to relocate and meet a potentially new team in the night, and they may or may not have any facilities available to stay with their baby that night.	*Repatriation, in most instances is a planned event and therefore should happen during normal working hours to reduce disruption for families.* *(included in the guiding principles section as last bullet point)*
15		The bit about multiples is too vague in my opinion, yes we know they may be separated short term, but giving a window of 24-48 hours means that's accepted as standard….that should be the exception, not the rule to work to.	*Agreed, time frame removed.*

Rob Nestor, Discharge Coordinator, St George's Hospital Robert.Nestor@stgeorges.nhs.uk

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7 &16	General	Minimum weight discrepancy between flow chart and criteria for LNU. We would prefer the lower weight of 800g, if stable.	*Flow chart amended*
24	General	Some of the links for the videos and posters do not link to the same place as the QR code, one directs to an advert only.	*QR codes checked and are working*
Repatriation YouTube Video	General	Makes some comments that may be inaccurate. e.g. the Local ODN transport team won't always do the transfer, sometimes it will be the Hospital Neonatal Staff and another ambulance team. Says parents will always be offered a chance to visit the local hospital before transfer. I understand this is a nice idea, but in practice, that is not always going to be possible, in fact, it is rarely going to be possible.	*Video is an example of best practice, groups understands that local arrangements will vary*
General	General	Does not indicate what escalation pathways/plans will look like/should look like. An example would be helpful.	*This is up to ODNs to decide*

Dominic O'Reilly, Consultant Paediatrician, Forth Valley Royal Hospital dominic.oreilly@nhs.scot

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7, 16	General	The weight criteria mentioned on your flowchart in page 5 do not match those on page 17.	*Flow chart amended*

Claire Richards, NHS Wales Health Collaborative Claire.Richards3@wales.nhs.uk

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16	Corrected gestational age	why are multiple different by 1 day?	*Agreed. Amended.*
16	Weight criteria	Can a baby be 1000g but less than 31+6/visa versa?	*Both criteria should be met before repatriation*
23	General comment in relation to family refusal	I completely understand that families are scared about repatriation/capacity, and this section is very important and useful to support staff in counselling and supporting families during this process. However, it is a UK problem that some families, despite staff best efforts in the above, just refuse. This causes huge problems for capacity, unit safety and increased IUTs if a cot cannot be created. Is there something that could be added into this document to support unit staff when these situations arise?	*We acknowledge this as an issue, however, as a national framework for good practice it is not appropriate for us to make a 'one size fits all' recommendation.* *Provider units should have local guidance to address this issue*
24	Repat video	A video to reassure parents around capacity transfers would be really helpful.	*Outside the scope of this document.*

Becky Sands, Consultant Paediatrician and Designated Doctor for Safeguarding Children and Young People, Sherwood Forest Hospitals NHS Foundation Trust r.sands@nhs.net

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15		I like the guidance but think there is a gap around advice for professionals when there is involvement of multiagency teams such as children's social care. Where there are safeguarding or child protection concerns it is important that there is liaison regarding this between referring and receiving unit, between both Trust safeguarding teams and with the responsible local authority. In most instances the child protection concerns are likely to make the referral back to the unit closer to home even more of a priority but this should be explicitly considered as part of the process.	*Added a bullet point in page 15 under Communication between provider units section;* *Where there is safeguarding concern and/or multi-agency involvement in infant's care this should be communicated in a timely manner and dialogue encouraged between relevant professionals*

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General	General	I am supportive of the general principles set out in this guideline, which tally closely with our network guidance (for the South West Neonatal ODN). There are a couple of discrepancies or areas requiring clarification within the document.	*Thank you*
P7 / P 16	Flowchart / Table	There is a discrepancy between the recommended weights for repatriation in the flowchart on P5 vs the table on P17 Specifically, the flowchart suggests weight of >1000g for repatriation to an LNU (too high in my opinion) compared to 800g in the table on P17. I would support consideration of repatriation from 800g, given the other criteria are also met. Requiring 1000g will have a significant negative effect on LNU activity, family displacement and NICU capacity. There is a similar discrepancy for SCUs (1200 vs 1000g) – this is less critical to my mind but still needs consistency	*Flow chart amended*
P16	Table	'Volume of feeds' – 'half enteral feeds' is pretty nebulous, and I think would benefit from an actual minimum tolerated volume e.g. 60 ml/kg/day	*Stating an exact volume can be too prescriptive and current statement is more balanced*
P16	Table	MRI following cooling – I'm unclear why some SCUs with appropriate facilities might not be able to undertake MRI in a stable infant. Many of the hospitals which host SCUs would undertake MRI for paediatric patients, and I think the level of facility/capability from a neuroradiology perspective is more relevant than the level of neonatal unit.	*MRI following cooling –* *Yes for both LNU and SCU* *(network level decision, based on available resources)*

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Pg 9	Last line	Practitioner Psychologist – ? to remove the word practitioner. Parents are at the end of the list of professionals, should they be higher up as the aim is for them to be at the centre of the process (ref page 6 – introductory paragraph).	*Multidisciplinary (MDT) involvement from referring and receiving units should include: parents, neonatal transport service, lead consultant, lead quality nursing roles (FiCare, Discharge Planning etc), AHPs, and Practitioner Psychologist*
Pg 11	14-17	Bullet point starting "Reasons for delays to clinical readiness…" Bullet point starting "Monitor/audit defaults…" We think robust monitoring of this needs to be clear and robust – who should be collecting the AHP data? Should this be local units or local AHP services. Is there a system for this data capture?	*It is under network responsibility.*
Pg 11	Under heading NICUs	Could bullet point 2 and 3 be combined? Putting families at the centre rather than "involved".	*Ensure repatriation planning starts soon after admission and includes parents in the discussion*
Pg 12	LNU/SCUs	Add a bullet point about parents visiting the local unit or virtual tour as on diagram on pg 5	*Add a bullet point - Offer virtual tour or parent visit prior to repatriation*
Pg 13	Bullet 4 last two lines	Consider rewording – less experienced… maybe change to complexity of case?	*Removed the term 'less experienced'*
Pg 13	Last bullet point	Add the word Badgernet before "discharge letter".	*Units may use different systems therefore left it generic*
Pg 14	Communication Line 1	Remove the word "Good" – Trauma informed communication should inherently good.	*Removed 'good'*
Pg 14	Communication with families	Add a bullet point about having difficult conversations to be held where there is no AHP team or not the specialist required in the local unit. The emphasis of the document is being open and transparent in communication so this does need to be part of the communication with families to help manage expectations and decision making.	*Refer to earlier comment and response*
P15	Communication between provider units	Suggestion of a section here specifically about communication between AHPs/Psych between services, highlighting best practice would include the creation of network guidelines to standardise transfers between units.	*Page 15. Add another sentence after2nd bullet point. This should include regular communication between AHPs and psychologists, where applicable.*
Pg 15	Guiding principles	Innovative models of support could be considered and a few examples given. It would be difficult for AHPs to be able to	*Virtual MDTs are forums for support to the LNU/SCU AHP professionals. They are not for clinical assessments.*

	Last bullet point	change any management or recommendations without clinical assessment especially around establishing suck feeds. Time for giving virtual support would have to come from other funded services and could potentially mask the workforce issues.	*LNU/SCU AHP would have made the clinical assessment and will ask for MDT input in these virtual forums.* *Funding is beyond the scope of this document. Group would expect that this would fall within the remit of ODN*
Parent story	Patient story	This is great experience story – could consideration be given to put this more centrally in the document rather than in the appendix?	*Parent story moved to the front of the document*

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16	Corrected gestation	I don't understand the rationale for SCU's to accept singletons at >=32 weeks yet multiples sooner by 1 day at >=31+6 weeks	amended
16	Vol of feeds	For LNU add 'acknowledging there may be slight instability in feed tolerance post transfer'	Current wording is sufficient.
16	MRI after cooling	Unclear what this means. Does this mean that the LNU may be expected to do the MRI post cooling? If so, I would be against this. HSIB has had cases where the post cooling MRI has not been done in an appropriate manner & the report has been done by a non-specialist	Wording amended. MRI following cooling – Yes for both LNU and SCU (network level decision, based on available resources)
16	Criteria for transport	I would include a section that covers the eventuality of a non-specialist transfer team undertaking the transfer. This should be associated with a triage/safety tool as exists in London due to lack of specialist transfer service capacity 'safety net' tool	Does not meet service specifications and therefore cannot be recommended in the framework
17	Out of area	Responsibility for transfer sits with booking hospital regional transfer team	Agreed. Responsibility of transport of these infants sits with the home network
17	IPC	Transfer teams also need to be informed in case deep cleaning of the transport incubator is needed between patients to avoid cross-infection	Transport teams should have these processes already embedded in their guidance/workflows.