

Name: Shavin Chellen	If you are answering on behalf of an organisation please state:
General comments: Haven't read the whole document yet, but looks good	Working Group Response:
Specific comments: I wanted to ask about the following sentence on page 34.	
"Using this approach, a baseline recommendation of one WTE member of nursing workforce per 800 births was established. The lead Neonatal Outreach Nurse role must be additional to this." Does the term births relate to all births in the region looked after by the neonatal unit. Or births that require neonatal admission?	The figure relates to all live births per Trust, system or region.



Name: Gina Outram	If you are answering on behalf of an
	organisation please state:
General comments: Excellent comprehensive	Working Group Response:
document , a lengthy read , but really good to	Pg 11- States named consultant has oversight
see that the forward was written- by a service	of neonatal outreach service and they are part
user	of the neonatal acute team.
Specific comments:	
Governance section	
page 11 - more clarity about	
accountability/responsibility for management	
plans and sign off - is this the responsibility of	
the GP or Hospital Consultant ?	
Page 12 - last bullet point ref patient safety	Pg 12 – Added
incidents should you include wider	
stakeholders e.g GP's , HVs and or Community	
Midwives ?	
Supporting families to transition to home	
section	
page 18 - include Open access criteria and	
opportunities to room in prior to transition to	Pg 18 – Added
home, out of hours medical support	
Maintaining Skills and Competence section	
page 26 - include shadowing maternity staff in a	Pg 26 – community midwives and pharmacy
TC care setting , MDT shared learning	added. AHP's already in document
opportunities with community midwives and	
HV's AHPs Pharmacists etc e.g SBR's , feeding	
plans , home phototherapy , developmental	
care plans, medicines management - 3 year	
delivery plan recommends learning together to	
reduce silo working and improve patient safety	
AHP Pharmacy workforce section	
page 36 states :"Urgent focus must be given to	Pg 32 – To limit this being a limiting factor in
fully establishing acute unit AHP and pharmacy	developing outreach wording changed in last
workforce standards before the outreach	paragraph to clearly acknowledge AHP
workforce is developed."	workforce levels in the units having a
Is this a realistic expectation or a limiting factor	significant impact on needs in the community.
in development of Outreach services ?	,
Would agree that the outreach service would	
not be gold standard without AHPs but disagree	
that this is should limit the development of	
outreach services.	



page 47 - example of good practice in Medway - it states the following	Pg 47 - Amended
"At discharge the team will be present on the day to ensure parents are prepared, resus	
training given alongside other discharge tasks, e.g. safer	
sleep. The nursing team complete other parent	
teaching like bathing, making up formula, medication giving, etc.)."	
I would question that this is good practice on	
the day of discharge , when parents are stressed , surely this should be done prior to the day of	
discharge	
Really like the Peterborough City Hospital East of England Model	

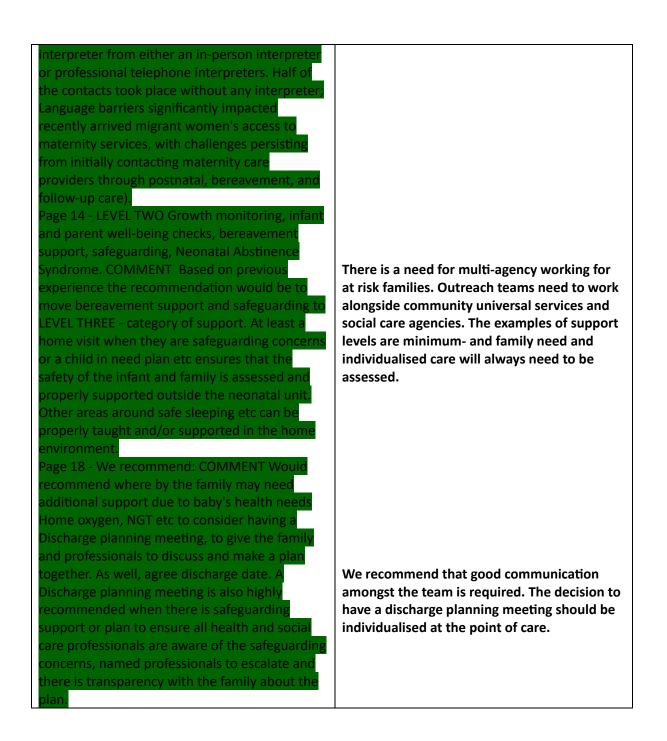


Name: Tendai Nzirawa	If you are answering on behalf of an
	organisation please state:
General comments: Thank you for taking time	Working Group Response:
to put together this working group and putting	
together this document.	
Based on my reading, there is no mention about	
Equality, Diversity & Inclusion in general or even	Thank you- we have strengthened this within
considering conducting a Equality Impact	the document
Assessment when establishing any new service	
or making any major changes to ensure all	
families especially those that are likely to	
experience poor outcomes or who may be living	
in the most deprived have tailored neonatal	
outreach support.	
The title 'nurse' or 'neonatal nurse' was used	
very minimum in the document, at times no	
mentioned at all. Although the service is	
delivered by a multi-professional team, who	Nurses are key to delivering care - Focus is on
brings lots of support, expertise and knowledge.	the delivery by a multi professional team
Its important to ensure when a service is being	
delivered by the nurse for example home visit	
etc its clearly stated nurse/registered nurse QIS.	
According to the Royal College of Nursing,	
protection of the title of nurse is in the interests	
of patient safety as well as the profession. Based	
on some of the quotes and survey included the	
role of the neonatal outreach nurses is pivotal to	
the success of the Neonatal Outreach Teams.	
There needs to be clearer guidance around the	
ratio of only one Neonatal Outreach Nurse for	
every ??? infants as well the other members of	This is impossible to calculate in this way at
the team, Neonatal Outreach Nursery Nurse and	this time as babies needs will differ depending
AHP <mark>.</mark>	on care needs. More data is required to be
Page 34 Using this approach, a baseline	able to define this staffing need further.
recommendation of one WTE member of	
nursing workforce per 800 births was	
established. The lead Neonatal Outreach Nurse	
role must be	
additional to this.	Pg 34 Recruitment for the working group
Question:	followed BAPM processes. The Neonatal
1) At the start were there been any invitations	Networks Outreach Group also supported.
to the Neonatal Nurses Association and Bliss	Within that group there are parent



Baby Charity to be part of the Members of the	engagement leads, NNA members, and Bliss
working group?	representatives.
Specific comments:	
Page 11 - Each outreach service should have a	
senior team lead at local level. COMMENT its	
not clear who is the senior team lead is, is this a	
neonatal lead nurse, AHP or Neonatologist?	
Page 12 - Network/Regional Lead role for	
neonatal outreach services should report into	
neonatal	
network management teams and share	
practice/guidance with Local Midwifery and	Pg 11 This is detailed in the workforce section
Neonatal Service structures (LMNS's).	and signposted from pg 11.
COMMENT are you referring to Local Maternity	
and Neonatal System - part of the Integrated	Pg 12 Wording changed to both.
Care System or the hospitals or both?	Highlighted in last paragraph that Patient
Page 12 - Patient safety incidents (including	safety incidents should follow local reporting
medicine incidents) should be reported, and any	procedures.
	procedures.
learning shared through provider trusts and	
network governance procedures. COMMENT	
will this link to The Patient Safety Incident	
Response Framework (PSIRF), if so this is the	
opportunity to mention it so that the Neonatal	
Outreach is not in isolation of the wider work	
happening in the Trust and National.	
Page 14 - Contacts and translation services -	
COMMENT This section does not mention	
anything about ensuring that where possible	
enough should be made to book face to face	
interpreters. Sadly, there is worse outcomes	
from women/birthing people who are migrates	
or request interpreter however do not always	
get the support.	
(According to The MBRRACE-UK collaboration,	Thank you for raising this important point.
which is co-led by the TIMMS group at the	Pg 14 face to face interpretation where
University of Leicester and Oxford Population	possible added to document.
Health's National Perinatal Epidemiology Unit,	
published the results of a confidential enquiry	
into the care of recent migrant women with	
language barriers who have experienced a	
stillbirth or neonatal death. 96% of the women	
had a documented need for an interpreter but	
73% of documented contacts with healthcare	
services took place without a professional	







Name: Suzanne Sweeney	If you are answering on behalf of an organisation please state: London Neonatal Operational Delivery Network
General comments: A well written and thorough resource which will be very helpful in the development of much needed neonatal outreach services - Thank you for drafting this guidance. General note - Throughout document 'psychologist' might be best replaced by 'registered psychological professional'. This is important because the other roles are all protected titles but 'psychologist' on its own is not, and we need to ensure the right staff with appropriate training and qualifications are	Working Group Response: Thank you - amended
taking on these roles.Specific comments:Page No: 11 Leadership in Outreach -Regional/Network LevelWhilst the network welcomes guidanceregarding the development of a designatedregional/network lead role for neonataloutreach/oversight of services there is no clearmechanism for the funding of this role. Whilstwe appreciate that this guidance is aspirational,given the current financial constraints onregions, it is unlikely to be funded at this time,placing additional pressures on networks withvery limited funding. It would have been helpfulfor ODN leads to be consulted on this prior toadding in the guidance.	Pg 11 There is ODN representation on the BAPM Working Group. This is a national document across the whole of the NHS. Whilst we agree funding stream has not been identified it should be considered as part of the leadership structure at network level. Commissioning is out of the scope of this document.
Page No: 7 - We would like to add to the sentence as compassion is mentioned in the 3 year delivery plan and has shown to be lacking The aim of these key recommendations is to ensure that all outreach services are safe, high quality, compassionate and continue to develop to meet the needs of the babies and families. between points 5. And 6. We would like to add an extra key recommendation All outreach services are delivered in a psychologically informed way, also bringing the principles of	Pg 7 Added



family integrated care, compassionate care and	
compassionate care into the work done in the	Added to recommendation 2
home with families.	
Page No: 9 - V minor, but on the first quote in	
the blue box, the quotation marks at the end	Pg 9 Quotation Changed
need deleting. Could add a paragraph here	
about the evidence base and policy directives	
for developing psychologically informed	
services. This could sit between the two quotes	Thank you for this comment. We have
or just below them. Something like this:	included the need for psychologically
Multiple recent reviews and directives (e.g.	informed services in the section on education
Ockenden review, Kirkup review, birth trauma	and training.
enquiry, pre term birth enquiry) have	
highlighted the need to provide compassionate,	
trauma informed neonatal care. There are now	
plans and projects in place to deliver this kind of	
care across all neonatal units in England,	
recognising that the care delivered to families	
needs to be consistent, considerate and with the	
parents and baby's history, needs and	
challenges held in mind. Staff wellbeing is vital	
to the delivery of psychologically informed care	
in neonatal units and the same is true for	
outreach services and those which develop in	
the future. It is no longer enough to deliver	
medical care without attending to the holistic	
needs of infants, families and staff. This will	
need to be a key consderaion as outreach	
services develop, with all staff having the	
training and support they need to deliver	
psychologically informed care in every	
interaction and clinical service delivery. At the	
point of care, this demands minimal additional	
time or resource, but it requires robust	
planning, training and ongoing support for	
teams.	
Page 10: bullet pointed list. Under point 7 (-	
improves family experience) It isn't just	
financial pressure that is reduced but also	
psychological pressure. Can we add this to the	
sentence?	Pg 10 - Added
Page 11: 'leadership in outreach' section. really	-
good to include this section. Can we add to third	
bullet point:	

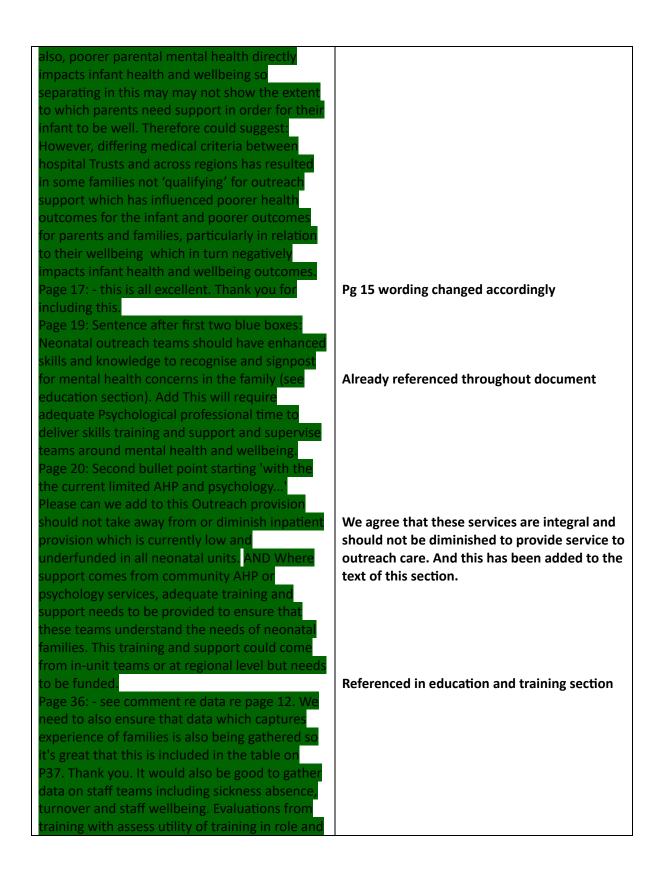


Cultivate a culture of safe, compassionate outreach and hospital at home practices. Page 12: - under 'information governance' do	Pg 11 - Added
we need to consider how this might work when the parents are the focus of care (for example if they have a mental health need and are being referred to an appropriate service?). Can we add a point about contributing to the parents' notes where necessary?	Pg 12 Added
under 'reporting' it would be good to have something here which acknowledges that national and regional data sets gather important data, but not always the data which matters to parents (e.g. How consistent their care was, compassionate care, being listened to etc). It would be good to have a way of capturing the things that matter to families, because we know that the data which is captured often becomes what is valued, instead of what might be really important to good quality services.	Added service user feedback to reporting section (also discussed in data section)



Name: Suzanne Sweeney	If you are answering on behalf of an organisation please state: London Neonatal Operational Delivery Network
General comments: N/A	Working Group Response:
Specific comments:	
Network Feedback Part 2	Pg 13 Wording changed and Appendix K link
Page 13: - excellent list. We worry about	added to text
'parental wellbeing checks and follow-up	
because I think many universal services and	
neonatal outreach/follow up clinics would say	
they were already doing this, but this is not	
being done in a robust, evidence based or	
appropriate way. Can this sentence be made	
stronger to highlight that 'and how are you	
mum?' isn't enough to assess parental wellbeing	
and functioning. Perhaps something like 'Robust	
parental wellbeing checks and follow-up from	
appropriately trained staff (including signposting	
and support to access community mental health	
and other services), or having a similar caveat as	
you have on the 'bereavement support' bullet	
(with appropriate training and supervision in	
place for staff to provide this at a universal level)	
Page 14:- really pleased to see section on using	
translators and families with low literacy. Thank	
you for including.	
Peer support groups are undoubtably helpful.	
Guidance on these is important to ensure are	Peer support groups recommended are
participants are safe and kept well. Could the	facilitated and organised by outreach nursing
guidance just allude to the need for governance	staff so fall under the governance processes of
and support around these groups.	the service.
Page15: Penultimate paragraph sentence	
However, differing medical criteria between	
hospital Trusts and across regions has resulted	
in some families not 'qualifying' for outreach	
support which has influenced poorer health	
outcomes and parental wellbeing.	
We are not sure this fully captures the issue.	
Separating out parental wellbeing makes it	
sound as though this is not a health outcome,	
when in fact I would say mental health and	
wellbeing outcomes are health outcomes. But	







quality of training would also support us to offer	Agree data collection of this is important but
the right training to these teams and to	should be a wider neonatal data collection
universal services teams.	and outside scope of this document.
universal services teams.	and outside scope of this document.



Name: Rebecca Davidson	If you are answering on behalf of an organisation please state: Pre 5 complex needs team NHS Lanarkshire Scotland
General comments: The document looks detailed and informative. It encompasses the need for a wider multi-agency team which is reassuring.	Working Group Response:
Specific comments: It may be helpful to know that the UK Speech and Language Therapy CEN for neonates who determined the algorithm for numbers of SLT in neonatal units is currently focusing on an algorithm for SLT whole time equivalents required to support neonates within the community setting.	Thank you for this information



Name: Jacki Dopran	If you are answering on behalf of an organisation please state: Herts and West Essex Local Maternity and Neonatal System
General comments: Thank you for this framework draft, it is long overdue and a really excellent document Specific comments: On page 19, Safeguarding, really good to see the information on lone workers. Our LMNS has a	Working Group Response:
community working group to support development of outreach work and the factor that comes up most frequently as a risk, is the lone working and lack of oversight in the Trusts to support their workers, often the Trust security and corporate teams are not aware there is a neonatal outreach service. Please could there be additional detail around documented risk assessments for lone worker for visiting babies and families homes, this could include interfaces to the wider hospital groups who undertake outreach and full awareness of "no-go" areas in the community foot print and also where x2 workers should attend . We also found that some outreach services were sharing mobiles and the quality of the phones was poor, a comment around appropriate apps and quality of mobile of devices would be very valuable. The RCN guidance is very valuable see: https://www.rcn.org.uk/Get-Help/RCN- advice/prioritising-personal-safety.	Pg 19 – Thank you for the information. The need for risk assessments included.
Data: The neonatal Badger system has a community module which in HWE we have found to be very supportive for base line data. Historical commissioning QIPPs may also be of help in data gathering to get a base line, as these looked at LOS for booked and born babies and strongly supported pathways to the community setting - great for the babies and families Thank you again to the BAPM and the working group for this work.	Thank you for this information.



Name: Maria Francis	If you are answering on behalf of an organisation please state:
General comments: Largely a positive step in the drive to improve and standardising community care Specific comments: Not specifically localised, although relating to the educational needs of staff providing NCOT services. (Education and Training pg 26) Much is made of the need for 'servicesnot be seen as a separate entity but as part of this continuum of care' and the need for 'enhanced knowledge and skills in the care of babies' including an anecdote from a parent perturbed by the lack of careers inexperienced in the extremely preterm baby' but then advocate that nurses do not need to be QiS before working in the community setting? If NCOT staff are to 'be drawn from experienced staff' and the robust national drivers are that all nurses working in Neonatal settings be QiS, then having non QiS nurses is contradictory, and diminishes the quality of care offered to families in the community. Whilst there is a place for non registered staff, and learning opportunities for nurses pre and mid QiS, it is imperative that staff being tasked with decision making and potentially delivering 'hospital at home' services, be appropriately trainedergo QiS. Much work has been done to move away from the idea that QiS is only necessary to look after babies in acute critical settings, and is part of a continuum of learning essential for ALL registered staff in speciality. To not advocate for this in the framework would be a backward step in the continuing care of neonates post hospital discharge. No nurse leaving university is equips with the required knowledge and skills needed to deliver neonatal care , and to potentially offer an 'out' in term of core neonatal education should not be encouraged.	Organisation please state. Working Group Response: Thank you for this insight. The Framework group feel quite strongly that there are many groups of staff experienced in neonatal care who are non QIS. Non-QIS staff (including experienced peadiatric community nurses, health visitors and midwives) can have a role in outreach services with the support/supervision of QIS staff. The make-up of the outreach team will depend heavily on the size of the team, the level of services offered, and local population needs. The essential element of having non QIS staff working in outreach care are robust supervisory and escalatory pathways as well as a robust foundation training programme for all staff undertaking outreach support (see Education and Training section) This also supports career progression for nursing staff with a desire or flair for working in outreach care who may then take the opportunity to undertake QIS training whilst in the outreach role.



Additionally, can clarity be given re: the governance responsibility of any potential ODN Lead role. ODNs do not have governance responsibility for clinical services.	
	Wording changed in leadership in outreach section



Name: Claire Inglis	If you are answering on behalf of an organisation please state: Leicester Neonatal Service & East Midlands Network Lead
General comments: Feedback from Leicester Neonatal service in relation to the draft BAPM National Neonatal Outreach Framework & East Midlands ODN	Working Group Response:
1. Concern in relation to practically being able to offer the service to ALL families whom have experienced specialist neonatal care. Concerns this may dilute the service and affect the ability to provide the support to those in greatest need .Time to be able to triage the level of support required by ALL families in a large tertiary center.	Agree that meeting these standards will require local services review, development planning, and review of staffing capacity.
There needs to be a minimum standard nationally agreed outreach criteria that ALL units should follow and work towards (which is not clear in the framework) before trying to establish a service that is offered to ALL. Maybe a stepped approach whereby if a minimum standard agreed criteria is achieved then offer families ability to self refer in for additional support or staff consultant referral outside of standard criteria (However would need the additional funding to be able to deliver	The fundamental elements of care are detailed in the service delivery section of the framework. (pg 14 service delivery standards).
). Any additional staffing will of course also deplete QIS workforce of which there is a National shortage. Therefore best option to be able to deliver a robust equitable service nationally to a defined higher risk group or clear group of babies eg tube feeding , oxygen , phototherapy , All babies less than 32 weeks	This will have to be determined locally based on service model, elements of care offered, and staffing.
<1.8kg BW etc . Units can then be assessed as to whether they are meeting this before moving onto to deliver to All. Maybe a bit like a BFI or BLISS accreditation. Achieving Level 1,2 or 3 . Or bronze , silver , gold , platinum .	Out of the scope of the document



At the moment it is too woolly to be able to Must be responsive to local need and reflect ssess each unit & identify gaps or standardize the service delivery standards. There needs to be more guidance as to now to categorize the level of care provided, so Out of scope of document but NNOG plan to look at in the future. hat every unit records data in the same way. Daily like on badger or would weekly for each baby at home work better ? – recording the highest level for baby for the week. Categories of care – is this to be only Staffing recommendations are based on data applied to Outpatients? Or can it be applied to from services providing the full service family support pre discharge home? If not it is delivery standards. important to establish what workforce time is Categories of care are only applicable for required in addition to provide this inpatient patients in their own home. support / parental education etc . For example WTE for Inpatient work perhaps in addition to outpatient support . What is the visionary service to be offered in terms of bereavement or NAS? To be determined at local level. At what level of involvement eg Phone calls, Home visits post bereavement, treatment a Consideration needs to be given as to whether home for NAS or observation other services are meeting all needs of the What if another team already provides this individual family. A combination of services service in different units? input may be required. For example Home phototherapy maybe already be in operation but provided by community There is a maximum recommendation for Paediatrics or midwifery? handover to paediatric services by 6 months Home oxygen maybe provided by community post discharge. There may be cases where it is Paediatrics. Would the outreach team change appropriate for earlier transition to paediatric their practice to take over this care up to 6 services. months then refer on? Maybe already a designated bereavement ?Add in conjunction with local specialist service that keeps in contact with the family services. outside of Outreach? Perhaps support still required for Parents of multiples whom the outreach team would support families of surviving babies in the community. Therefore need the skills required. Maybe differences between services in each unit. Therefore clear defined level of support required in order to establish if more service provision is required. If he current service provider cannot provide a nationally defined level of support , do outreach compliment to fill the void .



Specific comments:	
Please see above comments in question 5	



Name: Kim Edwards	If you are answering on behalf of an organisation please state:
General comments: A very detailed comprehensive co-produced document the appendices can add some distraction to your chain of thought. The models of provision across hub and spoke and LMNS footprint were very clear and detailed. Obviously the quantification of the workforce will be an on going piece of work. Will this be done in parallel with the training and education requirements? Should it be mandated that all staff rotate back	Working Group Response:
into the unit for maintenance of skills and knowledge? The collaboration with the Third Party Sector . As one of the Lead Nurses involved with the	Out of scope of this document
work around increasing clinical placements for undergraduates it is good to see it identified in the framework as a placement opportunity In hub and spoke model consideration of line management responsibilities. The case studies bring the document to life. Thank you.	Thank you for your positive comments
Pg 11 Leadership in Outreach should the lead role have both leadership and management responsibilities of the team managing sickness and appraisals workforce planning etc	Determined locally- this will depend on the size and structure of the team/unit
Pg 12 Under Governance should you reflect coaching and mentoring as well as supervision and peer support.	Added

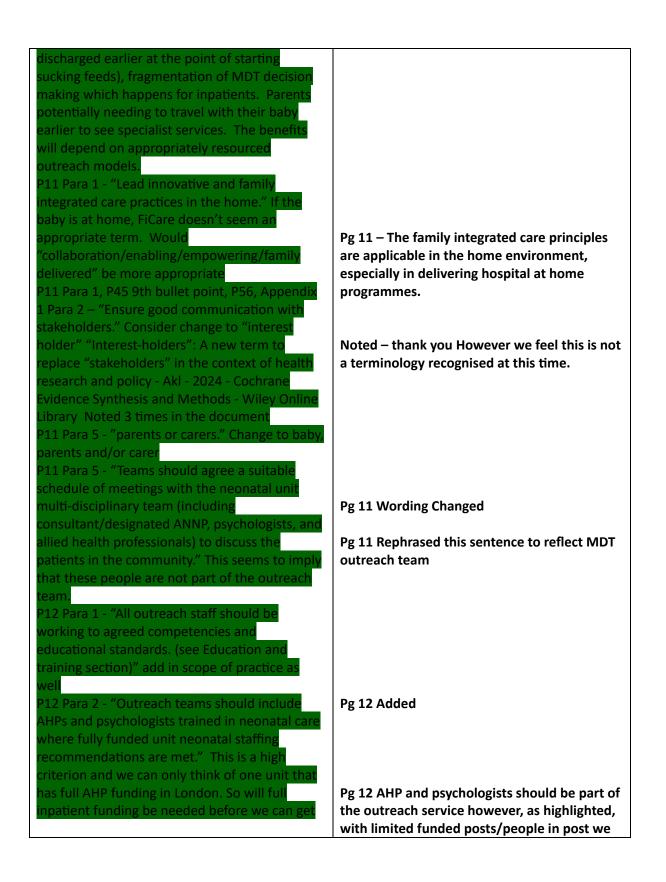


Name: Miles Wagstaff	If you are answering on behalf of an organisation please state:
General comments: I like it. Its quite long, and I must admit I haven't necessarily read the whole	Working Group Response:
thing word by word	Thank you. Formatting changes have been
Specific comments:	made
Some of the formatting needs tweaking - for	
example, on the 'summary of recommendations'	
page, some paragraphs have a space before the	
words start, others not.	
In the summary, some (most) recoomendations	
are 'should' or 'need to' or 'requires' - this is	
lacking in recommendations 10 and 12. I get	
they are recommendations, but they just read	
differently to the others.	
(Nothing major!)	



Name: Michalla Sweeting	If you are analyzering on babalf of an
Name: Michelle Sweeting	If you are answering on behalf of an
PDF	organisation please state:
RCSLT Neonatal CEN	Royal College of Speech and Language
& ODN SLTs commen	Therapists Neonatal Clinical Excellence
	Network and Neonatal Operational Delivery
	Network SLTs
General comments: Thank you so much for	Working Group Response:
including SLTs as part of the AHPPPs in this	The allower for a state of a sile sile
framework. We are delighted that there will be	Thank you for your positive feedback
a framework to guide commissioners and trusts	
in how to implement this service for babies and	
families. I am unable to submit all of the	
comments in box 6! So I will submit in parts.	
Any problems please let me know, I am happy to	
send in Word format if that is easier?	
Specific comments:	De7. No sustal system while inclusion of all
P7 Para 2 Bullet point 3 - Is this specifying	Pg7 – Neonatal outreach is inclusive of all
specialist neonatal outreach rather than services	members of the MDT supporting families in
provided by paediatric nurses, medics and	the transition to home as defined on pg 9.
AHP's? It seems an important differentiation to	
make	D-0 Outlined in a constal outpach definition
P8 Para 7 Scope and purpose - "support the	Pg8 - Outlined in neonatal outreach definition
development of services" should this read multi-	
professional services?	Pg 9 – This paragraph summarises the study in
P9 Para 5 - "working models of care" – should	appendix and funding not researched.
availability/funding of working models be noted	The references added have any surrout many
here as may not have AHP funding?	The references added here are support more than one element of the benefits of outreach
P10 Para 3 – "The evidence around neonatal	
outreach services is growing (see Appendix A	care and the working group felt it was not
and Appendix C for supportive literature)" - It	beneficial to link the evidence in this way
would be helpful if the evidence could be linked	
to the statements here even if it is the number	
of reference	
P10 para 3 – "Linking primary and secondary	
neonatal and paediatric services." Will there be	
any acknowledgement of the potential	Agree that the standards will require
challenges too if outreach is not appropriately	additional funding in some regions.
funded as a multi-professional resource e.g.	
reduced access to timely specialist feeding, AHP	
and Psychology support to optimise feeding	
outcomes. There will be the likelihood of later	
recognition of feeding difficulties (as they will be	





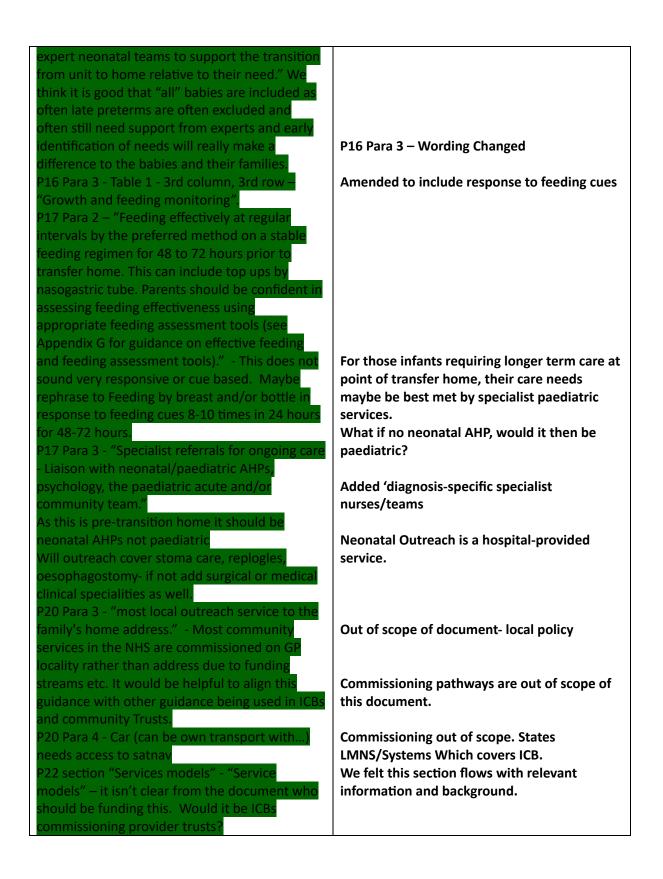


"additional" funding for outreach posts? This is what is implied here. P12 Para 2 "Additional funding may be required to further develop AHP and psychology services to meet the demand of support required by families under the care of outreach teams. In the absence of sufficiently funded services local escalation pathways should be developed." "will" instead of the word "may". Replace "under" with "as part of". Otherwise it	wanted to acknowledge that this will influence the needs of the families and the capacity of AHP's to care for babies in the community. Unchanged as there are some areas that are funded already.
sounds like the AHPs sit outside of the outreach team	
What is meant by "local escalation pathways"? P12 Para 3 - "Ideally, all notes should be	Wording changed
accessible to other community professionals such as GPs, Health Visitors and community AHPs." Could be linked to BAPM Electronic Health Record work.	Where there is no neonatal AHP local pathways of escalation should be developed, i.e. to paediatric service.
P12 Para 4 - Reporting - Is there an appendix	Pg 12 – Agree.
document that could give examples of suggested data collection points? Maybe with a	
hyperlink to Table 1	Pg 12 – Hyperlink added to refer to data section



Name: Michelle Sweeting	If you are answering on behalf of an organisation please state: RCSLT Neonatal CEN & ODN SLTs (part 2 of response)
General comments: See part 1	Working Group Response:
Specific comments:	
P13 Para 2 - "Growth monitoring and well-being checks." Does this imply to health visitors they no longer will need to do this? Is there a potential of loss of building HV relationship that is needed to continue after neonatal outreach have discharged that could be interrupted by	Pg13 – Working added 'In conjunction with universal neonatal services'
this and amended by a wording tweak? P13 Para 2 - "Infant basic life support training with parents/carers, safe sleep guidance and other health promotions." Would this be done before they transition to home or would the outreach team come in to the unit to do this? P14 Para 1 - "These can only be offered by	Pg 13 para – Health promotion advice can be given by either the unit staff or outreach teams. Meeting needs for parental knowledge and skills should be determined locally.
outreach teams operating a robust seven-day-a- week service:". How is robust defined? Staffing, MDT workforce? P14 Para 2 – "Direct face-to-face contact:" What about on the ward - one of the Bliss Baby Charter elements around meeting outreach teams on the ward before going home? What about the families that transfer at 44	Pg 14 Para 1 - Robust (dfn: able to withstand or overcome adversity) is a sustainable service offering 7 days a week care. I.e. contingencies for annual leave/sickness cover. P 14 Para 2 – Section wording changed to highlight section is referring to community care. Need for presence on the neonatal unit stated
weeks+ to children's wards? Would they be seen there?	in 'readiness to transition to outreach care' section
P14 Para 4 - Home visits – could AHP input not be delivered in the home as well as being mentioned in the Outreach Nurse led clinics. P14 Para 4 - "Peer support groups" – this does not need to be outreach nurse lead – maybe consider deleting as it could be run by a number	Guidance for families transferring from Neonates to Paediatric services currently under review. P14 Para 4 Home Visits– Locally decided dependant on best use of resources available.
of professionals or unit charities. P15 Para 1 - Video call – remove brand name "Attend Anywhere" as could be seen as marketing bias P15 Para 3 - "The vision for neonatal outreach	Other peer support groups are out of scope of this document P15 Para 1 – Removed
services is that all babies and families who have experienced neonatal care have equal access to	Thank you for your comment





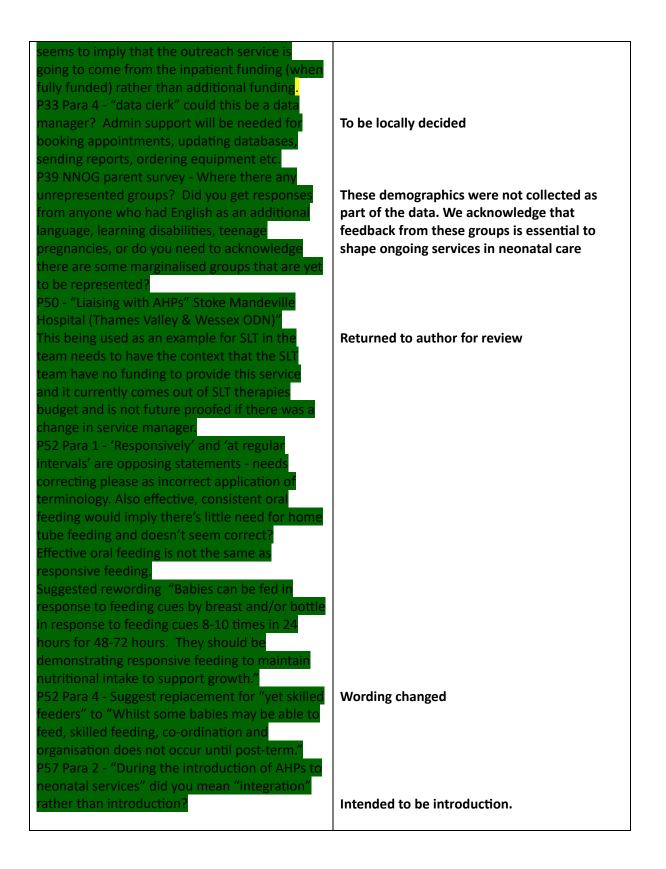


 P25 Table 2 – Should ICB's be mentioned here for commissioning services across LMNS's in the regional/network section P26 Education and training - There is some repetition in the document from the previous section on education – could they be combined to shorten the document and help with flow? P28 Table 3 - This seems to only relate to knowledge and skills for nursing and not to other HCPs such as AHPs and related competencies in line with their scope of professional practice working with neonates. 	Tabel 3 column one is core knowledge for <u>all</u> staff working in outreach teams. Profession specific expertise is referred to elsewhere in this section. Added text 'meet profession specific competencies for outreach care, where these exist'
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Name: Michelle Sweeting	If you are answering on behalf of an
	organisation please state:
	RCSLT Neonatal CEN & ODN SLTs
General comments: See part 1	Working Group Response:
Specific comments:	
Part 3 of 3	
P28 Table 3 Column 1 row 8 - "Basic awareness	Wording changed
of child development and movement patterns"	
consider rewording to encompass breadth of	
awareness of all core infant developmental	
milestones e.g. social-emotional, cognitive,	
communication, feeding and movement	
P31 Figure 1 – Shouldn't AHPPPs sit alongside	Thank you- we have amended
nursing colleagues on this diagram? Or	
otherwise as part of the team around the baby	
and family. The medical team is absent here as	
well. Maybe the diagram could be	
relationship/co-dependency based rather than a	
hierarchy shape? A gold standard service model	
would be ideal to depict here.	Wording changed to be clearer around
P32 Para 5 – "Even in those areas where staffing	additional funding required to support
recommendations are met there is often still	outreach services
insufficient capacity to take on the additional	
work required for outreach." Outreach funding	Funding for outreach services has yet to be
would need to be on top of WTE inpatient	determined for any discipline.
funding. This seems to imply it would come	
from a funded inpatient service.	
P32 Para 6 - "Urgent focus must be given to fully	This aims to reflect the development of
establishing acute unit AHP and pharmacy	embedded inpatient AHPP services will
workforce standards before the outreach	impact on early intervention, the neonatal
workforce is developed". This created a lot of	journey, education and upskilling of staff and
discussion from our members. We are not sure	families – which in turn will enhance
that this is the main reason for not looking at	transition to home
funding the AHP outreach workforce. Early	
intervention is important during the inpatient	Reworded the sentence to reflect this
stay but as the babies will be going home earlier	
they will need ongoing neuroprotective care to	
optimise outcomes including support with	Agreed that earlier discharge should not limit
establishing feeding. If anything outreach	the specialist support given to families.
without AHP support will take away what the	
babies and families could have received if the	
remained inpatients for longer. This again	







P57 Para 3 - integration into neonatal outreach services"- AHPs have already been providing these services with health visitors for many years P58 Para 3 – Speech and Language Therapist – section – we have contacted Beth SLT in	
Worcester, as CEN members to support with rewording her section directly. This will be sent to Sara Clarke as soon as possible for updating. P65 – post discharge – change to ?"transition to home"	
	Wording changed



Name: Emma Capewell	If you are answering on behalf of an
	organisation please state: NHS Highland
General comments: I am commenting on behalf of NHS Highland. Our Neonatal Unit is a level 2 neonatal unit, situated in Raigmore Hospital, Inverness. We have capacity for 14 babies or 16 points as defined by the British Association of Perinatal Medicine (BAPM) 2011. We admit between 200 to 300 babies a year for neonatal care. We serve the Highland Council area of 26484 square kilometres, including several islands, and we have the lowest population density in the UK at 8 people per square kilometre. Examples of travel times by car include 2h45min to Durness, 3h to Uig, 3h to Acharacle etc. We currently have a limited neonatal outreach service for 6 hours a week, offering telephone or video appointments to families of infants less than 32 weeks / <1500g BW / cardiac issues / terminal care. Babies on home oxygen or requiring long-term nasogastric tube feeding are cared for by the childrens community nursing team. Our geography and low population density make us unique within the UK and we would welcome any advice or input from your team as to how we might practically be able to implement your recommendations.	NHS Highland Working Group Response: Thank you for your comments. There will be a launch of this framework and supportive discussion on implementing recommendations to come.
Specific comments:	



Name: Dr Susan Kamupira General comments: Pathway for follow up of babies that are being discharged following surgical care would be good . Often these babies have prolonged admission on the neonatal unit and may have specific requirements e.g stoma care but also monitoring of growth and feeding support.	If you are answering on behalf of an organisation please state: Newborn services, St Mary's Hospital , Manchester University Hospitals NHS Trust Working Group Response: Thank you for your comment. The framework recommends all babies transitioning from neonatal care should have access to outreach care, alongside care from specialist teams as required.
Specific comments: Page 13-14. Service delivery standards- Outreach teams offering end of life care at home- this would require significant input into resources and would be better provided via palliative care service due to support required which may include out of hours work. Page 16 - Recommendation of telephone check on all babies transitioning home from neonatal care- it maybe useful for this to be provided to babies that have had more than a brief admission to NICU- We currently offer outreach follow up if babies have been admitted for more than 7 days.	Thank you. Wording changed to reflect outreach working alongside palliative care services. We are seeing increasingly shorter stays in TC as well as NNU. Our vision is for all families to have equitable access to outreach irrespective of the time spent in under the care of acute neonatal services.



organisation please state: Neonatal Network OT Leads group
Working Group Response: Thank you for your support and positive feedback.
All quotes stated are from parents who completed the NNOG survey. Stated in introduction.
Agree. To be locally discussed amongst teams.
Amended
Added
Community led or charity run peer support groups are out of the scope of this document
AHP's are inclusive of the outreach service so haven't segregated disciplines. Added development tot this service delivery



page 16 - Categories of Outreach support - would minimum level of support for babies with	Added to Contacts section
NAS fit better in level 3? page 32- AHP workforce-although important to establish acute AHPs as a matter of urgency - also important to consider requirements for AHP input into outreach at	This is minimum and level of need to be determined on case by case basis. If baby/carer required level 3 care this can be delivered.
planning/development of services - to ensure all funding options/models are considered . page 37 - Family experience: ensure feedback is from wide representation of families. Use EDI	Thank you – wording amended to reflect this
actively to achieve this. page 37 -Recommendations for data collection: says seek advice from unit/psych for tools for	Added
parent confidence, parent infant relationship and parental mental health- should also include OT as also specialists in parent/infant relationships	Added
page 62 OT support - maybe change parent engagement to family support - to highlight importance of family unit and recognize individual make up of family unit rather than	
solely parents.	Amended wording



Name: Julia Cooper	If you are answering on behalf of an
	organisation please state:
	East of England Neonatal Care Coordinators
	supporting EoE Outreach Group
General comments: *When more data comes in	Working Group Response:
we will be able to quantify a maximum caseload	Thank you for your feedback.
for outreach services, staffing levels, geographic	Increasing standardised data collection is
areas etc	essential to support future planning.
*Mentioning general support and advice, all be	
singing from the same hymn sheet as parents	
often mention they have conflicting advice.	
*Would be nice to integrate the Health Visitors	We actively encourage multiagency working
more, finding that they often step back when	to support transition home
we are in situ for weeks at a time.	
* The priority at the moment should be getting	Commissioning of services is out of the scope
	of this document
this service in place for every neonatal unit, rather than enhance the units that are already	of this document
able to offer an excellent service	
* Ensuring there is adequate staffing to meet	Agreed
the demands in the current climate will be	Agreed
extremely challenging without capital input	This is included in the decomposit
*There should be an agreed time limit to the	This is included in the document
service, e.g. neonatal commissioning 44/40	
*LMNS Hub and Spoke Model although a good	
idea in theory would not work when working	
under 2 ODN's	
*To implement the framework capital funding	
would be needed	
*Education package would be needed to	We hope to see this develop regionally and
support package - at regional or national level?	nationally with the publication of this
*A timeframe for full implementation would be	framework
helpful	Out of the scope of this document
*No mention of national tariffs	
Specific comments:	Current services offer a range of length of
	outreach care. The working group agreed that
*Page 7 Recommendations up to 6 months post	baby and family care needs are best met by
discharge - hoe are they funded post 44 weeks	neonatal teams until 6months after discharge
*Page 11 - Leadership - Network WTE	This will need further scoping and depend on
requirement not addressed	regional activity.
*Page 11 Governance - I love the fact that there	
should be a named consultant that has	Thank you for feedback
dedicated time allocated for oversight of the	

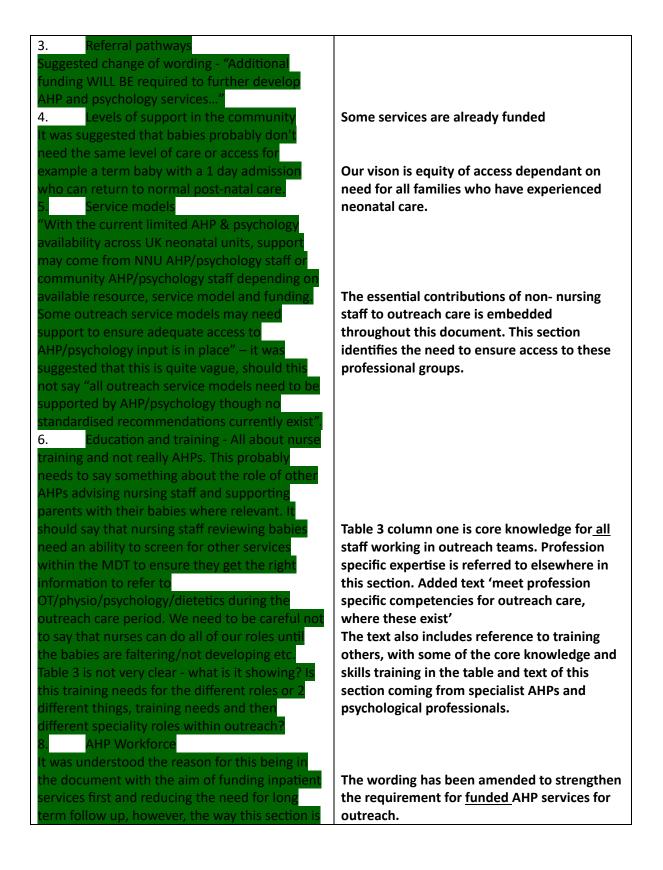


eviture characterization of a second time of a station of a	
outreach service as sometimes getting hold of a	
consultant sometimes can be challenging when	
things are busy even their named ones.	
*Page 13 - *Bereavement paediatric community	Consideration of supporting families with
teams are excellent at offering end of life care,	surviving babies from multiple births. As well
the neonatal teams can prepare babies for	as working alongside specialist services to
discharge but surely this specialist team are	support palliative care
better placed to give this care	
*Page 15 Parental wellbeing checks: I feel we	
don't always do enough of these and using the	Thank you
video attend anywhere again will most definitely	
help with this	
*Page 15 - Regular MDTs for caseload review -	Agreed
encourages positive working relationship	
*Page 16 - Having the Categories of Neonatal	Agreed – flexibility to meet baby and family
outreach support levels will be really helpful for	need
example it will reduce time on the road	
travelling to parents when a call may well suffice	
if parents are happy	
*Page 19 - Safeguarding families and staff- who	Refer to local policy on use of own car
pays for breakdown cover?	
*Page 33 Data collection and administrative	This will need to be determined locally taking
roles - WTE requirement not addressed	into consideration the role required and
*Page 33 Data collection - will there be a	service model of the outreach delivery.
national dashboard	
	This will be ongoing work linked via NNOG



Name: Hannah Cashin	If you are answering on behalf of an
	organisation please state:
	NDiG document review group and NDiG
	outreach/follow up working group
General comments: It is a great document and a	Working Group Response:
good start as a framework for outreach services.	Thank you for your positive feedback
Positive feedback around the quotes	
interspersed in the document, the infographics	
for the NNOG parents survey, the examples of	
good practice, and the examples to highlight the	
role of the MDT is really effective.	
Specific comments:	
1. Scope of the document - a general	
comment	
The definition of a neonatal outreach service	
(P9) clearly states that this service is a	The MDT group felt no further adaptations
multidisciplinary team of staff however it seems	needed. The document aims to highlight the
like the majority of the document is really about	need for multi professional working in this
nursing teams/structure/knowledge/skills. The	area
AHP and medical sections seem to be a bit of an	
'add on' and are either a bit vague or relegated	
to the Appendix. Clearly, reworking the	
document would be difficult however it may	
need to be highlighted early on that this	
document is really about nursing - maybe even	
in the title. It's a reflection of how NCOT	
services have evolved so far so maybe a future	
document would be more inclusive of medical	
and MDT guidance.	
2. Governance	
Teams should agree a suitable schedule of	
meetings with the neonatal unit multi-	
disciplinary team (including	
consultant/designated ANNP, psychologists, and	
allied health professionals) to discuss the	Specifics of interventions and outcomes for
patients in the community.	AHPPs are detailed in the appendices.
It feelt a bit vague bunching AHPs together as	And are listed in contents at front of
there is no explanation about the specific skills	document.
set that AHPs bring, however these are nicely	
explained in the appendices, so you could get	
through the whole document and not	
understand why we can improve outcomes.	





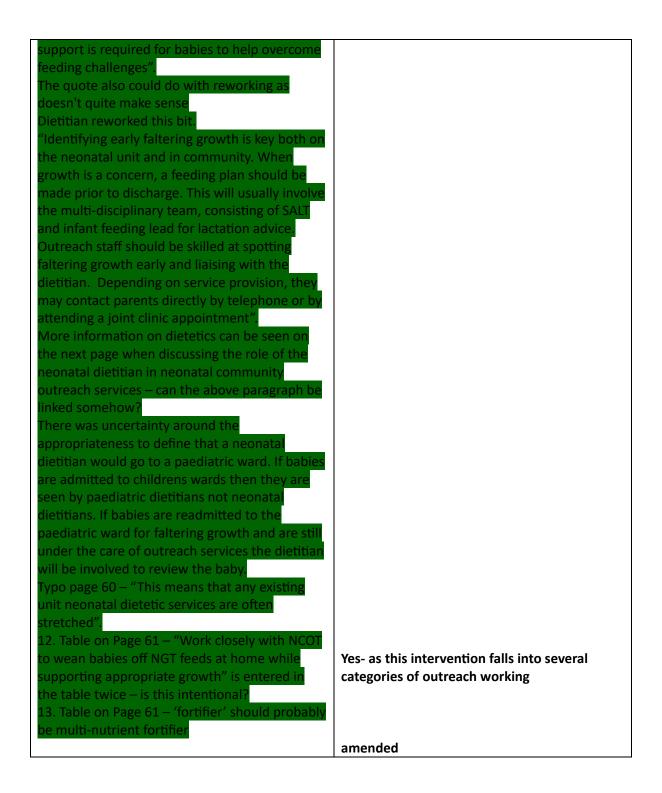


aid out under sells the essential input of AHP The need for a multi professional approach is eams who are being drawn into helping out integral to the success of outreach care and is nursing staff seeing babies in outreach settings embedded in the definition of outreach care as outreach services essentially provide and throughout the document as a additional capacity for hospital at home services fundamental requirement. similar to inpatient care as babies are d/c earlier To aid the reader's understanding of the whilst still transitioning to oral feeding and expertise of individual professional groups reducing down fortified milks prior to reaching and benefits in outreach care we have added erm age...this is later said as well but earlier in extensive details in the appendices. the document is not mentioned. The 2nd and 3rd priorities are growth and feeding, nurses are not infant feeding/ BF trained and as such I think we need to be saying more clearly that the dietitian would be the should be advising alongside infant feeding team where there are feeding difficulties. Local data collection on unmet need is advised 9. Data collection section on page 37 - It was to guide service development. suggested to separate number of referrals from number of contacts and collect both. This will nelp identify shortfalls in service provision.



Name: Hannah Cashin	If you are answering on behalf of an organisation please state: NDiG document review group and NDiG outreach/follow up working group
General comments: See previous submission.	Working Group Response:
	-
Specific comments:	
Submission 2 as I ran out of space on the first	
one. Continued	
10. Appendix H	
These are really good examples of service	Agreed- this networking/peer support is
models across the UK with useful detail on	available via NNOG
workforce. It would be really helpful if the	
services described were able to share any data	
on the demand on their services, numbers seen,	
caseload etc. Would be helpful for people to	
benchmark against when setting up new	
services.	
11. Appendix J	
Had to be read a couple of times by numerous people. It is actually a description of the experiences in Worcester rather than a general description of the role of the various AHP services. It could be reworded. The layout of this section is a little confusing specifically related to Worcester team and the next bit was dietetics in general. If the document was reworked to be more inclusive of the role of AHP services in outreach then these descriptions could be reworded and added into the main body of the document rather than the appendix. I suppose the lead authors need to decide whether it is essentially a nursing document or is more inclusive (see point 1 on previous submission). SLT	Thank you for your comments: but this is an EXAMPLE of AHPP working from an LNU. This is a review of how they have worked together to embed AHP & psychology services in their established outreach service. It is not a service specification, rather more personal experiences. Role descriptors for dietetics are included in this appendix.
"Prior to discharge a plan can be developed	
where needed where extra support is required	
when the baby is needing overcome oral feeding	
challenge" Suggested amendment – "Prior to	
discharge a plan can be developed where extra	





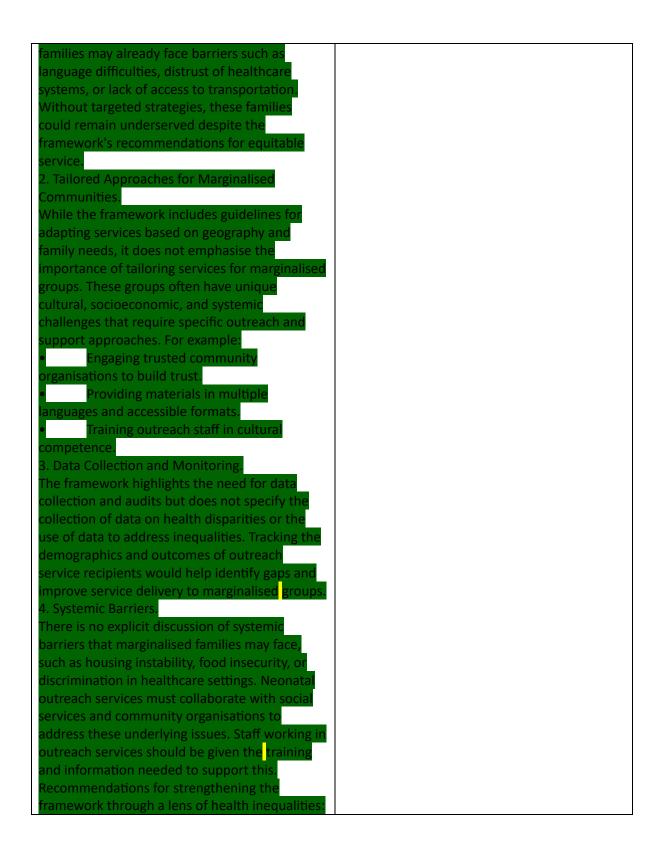


Name: Christian Chadwick	If you are answering on behalf of an organisation please state: NPPG: Neonatology sub-group
General comments: It is a long document with	Working Group Response:
an overwhelming amount of detail.	Thank you. As this is the first document to
The mentions of AHPs, psychology and pharmacy are confusing:	describe an extremely diverse service the working group prioritised the focus for the
Sometimes AHP is used to incorporate other	content.
professions, where sometimes all three are	
mentioned or only two (some examples are	Amended where necessary to ensure clarity
included in the specifics section below but not	
exhaustive).	
Specific comments:	
Page 3. Stephen McInerney is listed in the	Charles was not forward by the Neonetel
members as representing NPPG but we are not sure if that is accurate. Should be listed as his	Stephen was put forward by the Neonatal committee of NPPG for the NPPG stakeholder
job title because, although he is a member of	seat on the working group.
the NPPG, he isn't representing NPPG on the	sear on the working group.
working group per se.	
Page 4. TVW not defined on abbreviations	Added in full
Page 11 (final bullet point). could include clinical	added
pharmacist on list of MDT. Not covered by AHP	
Page 13. It's a good goal to have 7 days a week	Acknowledged
service but should acknowledge that various	
MDT roles are not even 7 days a week for inpatients.	
Page 16. no definition given for AHPPP. Assume	
it's AHP, psychology & pharmacy but pharmacy	Added and amended
hasn't been mentioned on the preceding pages	
(e.g. clinics on page 14).	
Page 23. Refers to AHPPs, which again is	
undefined but seems to be AHP and psychology.	Added and amended
No mention of pharmacy on this page even	
though pharmacy is mentioned on page 22.	



Name: Maya Parkin	If you are answering on behalf of an organisation please state: Bliss Charity
General comments: FICare: To ensure all readers have a good understanding of Family Integrated Care, provide signposting to a resource on, or an explanation of, FICare, Feedback mechanisms: One of the key recommendations is that	Working Group Response: Thank you - We have signposted to BAPM Ficare Framework for Practice
"neonatal outreach services should be responsive to parent/carer need and feedback", however there is no further explanation in the document regarding how to do so. It would be beneficial to strengthen this section to include an explanation of the importance of creating robust feedback mechanisms, which should be accessible for all families, seek to specifically understand the experiences of groups impacted by health inequalities, and that this feedback should be translated into tangible improvements to services. Health inequalities:	One of the fundamental principles of the document is that services are responsive to baby and family need. This is highlighted in service delivery and data sections. Further work on collecting parent/carer feedback (data) will be ongoing at NNOG and regional/network and local level. This is urgent and essential to inform service development.
A crucial consideration that is missing from the Framework is how Neonatal Outreach Services can reach, engage with and provide individualised support for marginalised communities. These groups disproportionately face barriers to accessing care. For example, Black and Asian families, families experiencing social deprivation, non-birthing parents and young parents below the age of 18. The following four points are suggested improvements for how to framework can be more cognisant of health inequalities. 1. Equity in Access to Services. The Framework recognises the existence of a	Thank you for this exceptionally important narrative around health inequality. The Framework group acknowledge the complexity of delivering services for these marginalised groups. This document promotes a service that meets the needs of all families who have received neonatal care. It supports multi agency working to ensure all families have equitable access to individualised care that meets the explicit needs of each baby and family. Service development must be in partnership with service users – and this is integral to the Framework.
"postcode lottery" in neonatal outreach care and acknowledges that geographic boundaries and service availability create inequities. However, it does not explicitly address how these inequities disproportionately affect marginalised communities. Marginalised	The framework group also acknowledge that the complexity of meeting the needs of marginalised families is not isolated to outreach care and should underpin all health and social care.







 Incorporate Equity Metrics: Require data collection on service access and outcomes disaggregated by socioeconomic status, ethnicity, and other relevant demographics. Targeted Training: Mandate training for neonatal outreach teams in cultural competence and implicit bias. Community Partnerships: Establish partnerships with local community organisations to better reach and support marginalised families. Parent Feedback: Ensure that robust feedback mechanisms are in place to collect and act on parent feedback to ensure that all voices are heard. 	
Specific comments: Page 18: 'Supporting families through the transition to home process' could include signposting to/hardcopy of Bliss' "Going home from the neonatal unit – a guide" booklet. This booklet is available to download from: https://www.bliss.org.uk/parents/going-home- from-the-neonatal-unit.	Agree- signposting to local and national resources should be included in knowledge and skills frameworks for parents/carers



Name: Jo Bruce	If you are answering on behalf of an organisation please state: Liverpool Womens Hospital Neonatal Intensive Care Unit
General comments: 1) I think this is a great and	Working Group Response:
much needed framework.	Thank you for your positive feedback &
My main issue is around virtual and telephone contact. For some families this may be appropriate. However, in families were there are	examples of care levels to inform the group
challenging social circumstances (neonatal	The decision around levels of care will be
abstinence syndrome is the one cited here),	determined by local teams based on family
more intensive face to face contact seems	need and multi agency team working. The
important to me. Sadly, we only have to look at	Framework group acknowledge that outreach
what is on the news almost weekly-baby and	service may not be able to provide every
child deaths, where the families were often	support/care needed by families and
known to many services but warning signs were	recognise the importance of multi agency
missed. I have personally encountered two	working in certain circumstances.
cases where health professionals were falsely	
reassured through virtual contact. Community	
outreach services are in a prime position to	
identify and escalate early concerns. I would	
therefore advocate for safeguarding,	
bereavement support and neonatal abstinence	
syndrome be escalated from level 2 to level 3	
support as per this framework.	
2) I would agree with thee above response	
regarding certain categories being escalated to	
sit under level 3 support and wonder if this	
could be fed back as part of working group.	
Many thanks for all the work that has gone into	
this,	
3) I think this sounds an ideal Follow up plan to	
aim for involving the whole MDT to support the	Thank you for your comments
needs of the family unit. Although, seems a long	
way off for us.	
In the shorter term, the idea of MDT drop in	
clinics possibly sounds more achievable and	
very beneficial to families.	
The parent peer support groups also sound like	
they are very well received by families	
Supporting all NICU babies and small baby	
pathway, including ngt, phototherapy would be	



 ideal but obviously need large increase in staffing numbers. 4) Its great and offers a staffing model for future business cases I think its way too long though There are too many examples of things at the end I am not sure people are going to read it all 	Thank you for your comments. We appreciate that this is a long document – but as this is the first time outreach has been described in such detail it was important to cover as many aspects as possible.
5) Amazing and long awaited framework with a lot of essential details. Staffing levels and appropriately trained and experienced staff are the principal starting point, and from there the service can then be extended safely and appropriately. Every geographical area will have their own issues and complications to work with, but once the service is able to work to a full capacity, staffing level wise, the framework leads to very successful support network for the families who need NCOT care to feel supported with their baby at home. Specific comments:	Thank you for your positive comments
Page 12: referral pathways/ escalation should include support from a dedicated neonatal	Agree- content reflects this
dietitian Page 12: information governance – there should be info available re: safeguarding aspects Page 12: reporting – NCOT activity/data should	Covered in service delivery- safeguarding section. Strengthened text here
be captured as part of the neonatal dashboard Page 13: service delivery – the future could include involvement in neonatal research	Recommendation to report to local and national data sets
support. Also involvement in surgical care (ex: wound management/stoma care/silo	Research included as key recommendation
care/broviac care etc)	Local services will determine specialist outreach care pathways



Name: Jo Bennett	If you are answering on behalf of an organisation please state: South West Neonatal Network Outreach Group
General comments: Very helpful framework with helpful examples of practice in the appendices and all information in the body of the framework supported by parent comments.	Working Group Response: Thank you for your positive feedback
Specific comments: Categories of neonatal outreach support level (page 16) Could there be more clarity in this section. Level	
one, single telephone contact – is that for all babies who had a neonatal admission e.g would this include a baby going home from the postnatal ward who was initially admitted to the NNU for 24 hours or so? Or is this for all babies discharged home direct from neonatal services NNU/TC?	Neonatal outreach should be available for all babies transitiong home from neonatal care (NNU/TC)
Is it too open e.g a 24 week infant who has had a good journey and being discharged home not on oxygen, looking at the table could indicate a phone call only. From a business case perspective, management may look at it and see the minimum level of support only. Some clarity that a baby can enter on any level of the table.	The desire is that baby and family level of care will be individualised, and needs met by the outreach service. The level of care may fluctuate during the baby's time under outreach service depending on need. This is included in the text of the document.
Calculating workforce requirements for outreach services. Nursing Workforce (page 33) Several teams have used this calculation and staffing levels seemed almost unachievable. Although recognise this might be gold standard and something to aim towards but could there be a staged approach in increasing staffing to work towards a 7/day service? Or is there another way of calculating staffing? We recognise that staffing needs to increase for the outreach workforce to be able to deliver a 7 day/week service. Is there also recognition of	Nurse staffing recommendations have been based on benchmarking of robust hospital at home services. There will need to be a staged approach for building teams to this level in terms of staffing and service delivery. We have amended wording in this section to reflect this.

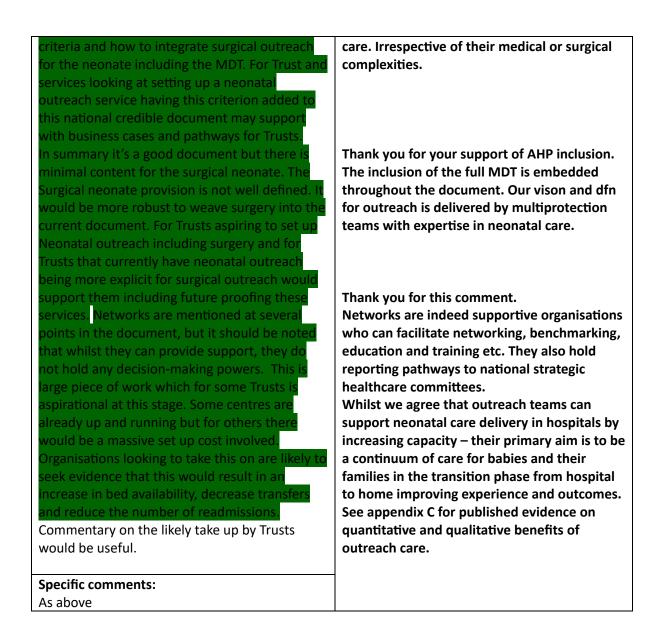


the complexity of care of infant needs that different services might see? Education and training (page 26) Point 5 on psychologically informed care, could there be recommendations for psychological training for outreach nurses e.g motivational interview training such as health visitors have.	Agreed- there are some resources for supporting neonatal teams in this area already. Further collaborative work will need to take place to develop local/regional and national training now that this has been defined in this Framework.
Transitioning from neonatal outreach services (page 20-21) The recommendation of 6 months is helpful to see, particularly where there can be some difficulty in transitioning infants on low flow oxygen to paediatric services.	Agreed



Name: Clair Scaife	If you are answering on behalf of an organisation please state: Y&H surgical in Children ODN
General comments: Submitted on behalf of the Y&H SiC ODN in response to BAPM neonatal outreach draft. 10.1.25 These are responses gathered from senior neonatal surgical nurses within the Yorkshire and Humber ODN. Collated by Clair Scaife Lead Nurse surgery in children Y&H ODN, with additional comments from Ian Sugarman Y&H Clinical Lead Surgical ODN. This is a lengthy document which provides a good framework for an outreach service for medical preterm babies within a Tertiary framework. It is easy to read and understand and is comprehensive. The Parent feedback is	Working Group Response: Thank you for your positive feedback
good. However, there is very little mention of surgical babies (only one reference to surgery in the document) which is an important omission due to the increased number of complex surgical babies surviving. Many neonatal surgical babies will go home needing surgical outreach service including surgical care at home such as stomal bowel washout and catheter care. This takes time to support families and neonates for this	Agreed- and specialist services to support these infants need to be developed locally alongside outreach care. Depending on the specialist services offered by the unit this may include surgical or cardiac specialists etc within the outreach team. This must be determined locally to meet needs of the population.
care. All babies can receive neonatal outreach from 5 days of life. However, it does not describe the criteria or define the patient. For the Surgical neonate there is no detail. For completeness the document should include surgery and neonatal complexities. The document describes medical preterm outreach babies and needs to have surgery weaved throughout document. Furthermore, it needs to have more MDT inclusion in outreach services including AHP provision. Our recommendations are adding and integrating to this document; Define patient, what is neonatal outreach, what fits outreach	The working group strongly recommends outreach services ALL babies and families who have experienced neonatal care have equitable access to outreach services irrespective of any co-morbidities. Those with ongoing medical or surgical needs may need additional support/care packages from other specialists or external agencies – but this is not in place of outreach care rather working together to provide care needs. The working group have moved away from 'criteria' for outreach instead are recommending equitable access to outreach for ALL babies who have experienced neonatal







Name: Fiona Metcalfe	If you are answering on behalf of an
	organisation please state:
	National Neonatal surgical interest group
	(NNSIG)
General comments: It is exciting to see this	Working Group Response:
document published. Well, done to all involved	Thank you so much for your positive response.
a big piece of work. Overall the NNSIG like the	
framework with its understanding of the needs	
for families and neonates. The models of service	
provision and delivery are well described and	
offers a good benchmark for budding services or	
those wanting to review their service provision.	
It aligns with all the national recommendations	
from NCCR, BAPM, 3-year delivery plan,	
neonatal critical care service specification.	
The evidence base for the need and benefits of	
neonatal outreach services, is well	
demonstrated and represented. You highlight	
the important need for audit and research	
moving forward to help understand appropriate	
service caseloads, acuity, and workforce needs.	
This is an equally important for provision for	
surgical neonates and care pathways.	
The main points to raise from NNSIG is around	
the surgical neonate and family. We	
acknowledge that the framework represents the	
preterm medical neonate very well. Whilst the	
document has many good recommendations	
and examples of service provision for preterm	
babies, there appears to be little discussion	
about the most complex babies such as the	
surgical neonates. There is a feeling that all the	
points contained within this document are	
applicable to surgical outreach also.	
Neonatal surgical outreach service is an	
essential specialist service required to enable an	
early, safe and effective discharge of complex	The working group agrees and equitable
surgical infants from Neonatal units.	access to outreach for all babies who have
Experienced surgical outreach nurses undertake	experienced neonatal care is essential. This
a wide range a complex nursing procedure	may mean service model that includes
within the home environment, which are	specialist nurses at local level to support this
currently not provided by the other universal	element of care for complex infants.



community services e.g. Health visitors and Children's community nursing teams, medical neonatal outreach.

I will list the points of feedback.

• The start of the document does not clearly define the patient population for neonatal outreach services. It does say: All babies and families who have experienced specialist neonatal care should have equitable access to a multi-disciplinary, robust 7-day a week neonatal outreach service to support their transition from hospital to home.

The document is not explicit enough about the service needs of the sick term, near term neonate, those with complex comorbidities or the surgical neonate. It seems to describe only medical, preterm needs. This is essential but needs to be broadened.

 Surgical neonates have specific needs which are different to medical neonates. They often require extended nutritional monitoring and dietetic input due to short bowel, gut dysmotility. We are seeing more of such patients due to increase in extreme preterm survival following NEC.

The document does not have AHP
 provision integrated and embedded within the pathways- dietetic is especially essential for
 preterm, term and surgical neonates.
 SLT's would like to flag that some families
 require specialist surgical neonatal outreach/
 transition care as a core part of MDT neonatal
 outreach as it's only very briefly touched upon.
 We really need these 'outreach' services to be
 integrated and collaborative across all aspects of
 the MDT and wondered if the nuanced specialist
 of surgical specialist nurses is maybe a bit
 under-represented.

 The surgical neonate is mentioned very briefly in one/two points only. The provision for the surgical neonate eg with a stoma, catheter, surgical feeding tube, wound care, VP shunt care and monitoring etc is not defined or demonstrated within the document. The working group strongly recommends outreach services ALL babies and families who have experienced neonatal care have equitable access to outreach services irrespective of any co-morbidities. Those with ongoing medical or surgical needs may need additional support/care packages from other specialists or external agencies – but this is not in place of outreach care rather working together to provide care needs. The working group have moved away from 'criteria' for outreach instead are recommending equitable access to outreach for ALL babies who have experienced neonatal care. Irrespective of their medical or surgical complexities.

Thank you for your support of AHP inclusion. The inclusion of the full MDT is embedded throughout the document. Our vison and dfn for outreach is delivered by multiprotection teams with expertise in neonatal care.

We have strengthened wording around specialist care for babies with complex needs.

The working group recommends ALL babies who are being transitioned to home from neonatal care should have equitable access to outreach. It is impossible to define all comorbidities within this document for the fear of exclusion. We have included some surgical examples in the levels of care table.



 There are tertiary services that run neonatal surgical service alongside neonatal outreach. A wheel and spoke model of speciality neonatal surgical outreach could be included to feed into existing regional/local neonatal outreach services as an example of a model. This may be aspirational for some centres but an important one to have an opportunity to support in the future. There are neonatal surgical outreach services in some tertiary centres but equally to neonatal outreach, 	The development of any specialist skill sets/services within or alongside outreach needs to be determined locally to meet needs of the population and an integral part of service planning and development.
Specific comments:	



Name: Cheryl Curson	If you are answering on behalf of an
Name. Cheryr Curson	organisation please state:
Concrel commenter I think this is a really great	Working Group Response:
General comments: I think this is a really great	
piece of work, and a good start to a framework	Thank you for your positive response
for NCOT services, which will need to evolve	
over time. Regular reviews should be scheduled	
to updated the framework as the landscape of	Agreed
neonatal care changes and some of the	
unknowns referred to in the document are	
resolved.	
Please proof read to ensure consistent tense,	Thank you for this feedback
punctuation and correct titles for national	
documents. This should align with other	
frameworks to ensure consistency of messaging.	
Parent stories are distracting embedded	The working group, including our parent
throughout the document- would suggest these	representative and family engagement lead,
are organised by theme and grouped together.	feel strongly that the quotes demonstrate we
Some the language does not adequately	are listening to families, support the text
describe the point being made e.g. holistic	content and recommendations within the
oversight (p11) and could be more concise.	document and 'bring the document to life'
The framework is comprehensive, but very long	threaded through the text.
and not always easy to follow in terms of flow.	Thank you – we have reviewed the text
Could the supporting info and exemplars be	
available in a separate document-70 pages is	
very long for a BAPM framework and those	Thank you for this feedback. As the document
without an invested interest may disengage.	is the first time neonatal outreach has been
	described in such detail there was a large
Specific comments:	amount of content that was essential to
Very powerful introduction from Emma	include.
Johnston	
It should be clearly stated that outreach is	
neonatal special care delivered in the	
community with parents empowered to be the	
primary caregiver- this should be consistent	
terminology in line with the FICare framework.	This is embedded in the definition of neonatal
There is inference that the ODN holds the	outreach. We have also linked to BAPM FICare
governance for providers of NCOT services- is it	Framework.
more assurance that is expected of ODNs given	
that they cannot hold or manage risk, or that	
they will commission NCOT services for their	
region? If services are expected to follow	
network guidelines as per the service specs-	



then this would require work to standardise and streamline across regions improving consistency	Agree- we were delighted to have amazing parent representation
of care for families.	
P11 Leadership- outcomes should be clear.	
What is cohesive vision, holistic oversight.	
P11 Leadership at Trust/ICB level - which	
professional group are we referring to-should	
be clear if this is a nurse or advanced	
practitioner or doctor. Is this service	
management or leadership or both?	Amended language
P12 P1 restorative clinical supervision and	
safeguarding supervision is required	
P12 patient safety incidents to include near	
misses- should be development of a standard	
trigger list for incident reporting related to	
broader care provision e.g. systems, processes,	
safeguarding of patients, families and staff not just patient safety	
P13 Service delivery standards-multi-disciplinary	Amended language
team planning should include health visitor, GP,	Amenueu language
social care/others as required . Some of the	
parent information and skills would be the	This section signposts to workforce for detail.
responsibility of unit staff prior to transition	Senior leadership can be provided by most
P13 Bereavement support- don't disagree as	appropriate professional group to be
agree this should be universal for ALL neonatal	determined by service model
staff and is included in the new neonatal	
education standard. What is the expectation of	
NCOT staff around this as it is very specialised	
area of care- are we anticipating future delivery	
of palliative and EOL care by NCOT teams as	
suggested (although only EOL not PC is	
mentioned)? There is currently not 24/7	Consideration of supporting families with
community children's nursing care for PC/EOL	surviving babies from multiple births. As well
care and an all-age approach to provision is a	as working alongside specialist services to
development to address this. This needs	support palliative care. We have added clarity
significantly more infrastructure and resources	on this point.
than just 7 day/daytime NCOT nurses so I feel	
this should be removed and included in a future	
version of the document unless it is worked	
through clearly here. Focus on getting the basics	
(including home phototherapy) embedded to a	
consistently high standard.	
P14 Outreach nurse LED clinics- relocation	
makes the logistics easier for the families too-	



cost, parking and travel time- additional stressor for families. Services are moving into the community, and clinics should follow the same model whether that uses community hubs, family hubs or an alternative. Co-location with the services that families need to access e.g. those available in family hubs allows broader support to be accessed more easily. P15 Levels of support in the community- I agree absolutely that every family should receive a check in on transition home after being admitted to the neonatal unit or transitional care. Not sure NCOT services are best placed to do this if they have not/are not going to be providing the ongoing care for the family. This should be in conjunction with robust discharge coordination or FICare leadership- it maybe the role of those professionals to touch base with families who are not going to require ongoing NCOT support- they will know the families better. Alternatively, a model where discharge coordination is embedded in the NCOT team, or where staff work between NCOT and the unit so they know the families on the unit before they go home.	Agreed Agreed thank you for this feedback– the logistics of the delivery of this will be dependent on local pathways
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Name: Cheryl Curson	If you are answering on behalf of an
Concerci commentes Ac provinse recordence	organisation please state:
General comments: As previous response	Working Group Response:
Specific comments:	Repeated comment
P14 Outreach nurse-led clinics- relocation also	
makes the logistics easier for the families too-	
cost, parking and travel time- additional stressor	
for families. Services are moving into the	
community, and clinics should follow the same	
model whether that uses community hubs,	
family hubs or an alternative. Co-location with	
the services that families need to access e.g.	
those available in family hubs allows broader	
support to be accessed more easily.	
Page 15 levels of support in the community- I	
agree absolutely that every family should	
receive a check in on transition home after	
being admitted to the neonatal unit or	
transitional care. Not sure NCOT services are	
best placed to do this if they have not/ are not	
going to be providing the ongoing care for the	
family. This should be in conjunction with robust	
discharge coordination or ficare leadership-	
maybe the role of those professionals to touch	
base with families who are not going to require	
ongoing NCOT support- they will know their	
families better. Alternative is a model where	
discharge coordination is embedded in the	
NCOT team, or where staff work between NCOT	
and the unit so they know the families on the	
unit before they go home.	
P21 Parentcraft- Outdated term, please change	
to parents skills/information/knowledge. This	
should be embedded from the beginning of the	Amended
baby's admission, individualised to the families'	
needs. Parents should be confident to be the	
primary caregiver well before transition to	
home- NCOT and HV can support additional	
learning.	
P21 NCOT should not just have an awareness of	
support networks available for families in their	Agreed, additional wording added
adport networks available for families in their	



local area but be actively building good	
relationships with the services.	
P21 Service models	
What is the definition of a continuous 7 day a	
week service? a 24-hour seven day a week	Service should be available every day. Hours
service, or daytime hours e.g. extended daytime	to be determined by local need and staffing.
8 till 8 or a shorter e.g. 8-5. This should be	Added to document
clarified.	The recommendation is all services require a
What is the role of Nurse Consultants in NCOT	designated consultant lead for escalation of
services- an ANNP would still require consultant	concerns and to support service development
supervision and support.	and delivery.
Accessible services- needs to be consideration	
of all the vulnerabilities and individual need of	Strengthened language
families e.g. cultural, disability, learning needs,	
care experienced	
P22 all service models must follow a	Roles and examples of intervention/support
collaborative approach- the expectations and	of AHPs and psychological professionals
role of each professional group needs further	working in outreach care are included in the
clarification	appendices and in development by
P23 network/regional hub-recognition that this	professional bodies
might lead to efficiencies, improve consistency,	
reduce unwanted variation in services- all	Added
models will need strategic leadership and	
administrative support.	The terminology used here is to distinguish
P26 Education and training	between QiS qualified neonatal staff and
This should mirror the new education standards	other nursing staff who may be employed
and avoid referring to QiS/Non-QiS - this is	within outreach teams such as community
unhelpful	children's nurses, midwives, and/or staff
l agree education and training must be relevant	nurses working with health visitors
to outreach care but staff must be supported to	
access other neonatal training that will allow	
them the ability to professionally	
develop/maintain skills in acute care, not be	
limited to working solely in outreach care which	
could limit flexibility and be career-limiting	
(feedback from survey conducted in region	The working group agree with this comment
highlighted NCOT staff want to access a broader	but felt this was outside of the scope of this
range of education)	document
ange of education y	



Name: Cheryl Curson	If you are answering on behalf of an organisation please state:
General comments: As previous	Working Group Response:
Specific comments:	
P26 Core knowledge and skills for outreach staff	The working group felt the core knowledge
will differ whether registered or non-registered	and skills provided baseline knowledge and
staff	skills for ALL staff working in outreach
P28 Disagree with the content in table 3, this	services, irrespective of professional group.
needs to be reviewed. Many of the enhanced	······································
knowledge and skills listed are actually core	Thank you for your comments. The working
skills for working in a unit or community setting.	group felt it important to define knowledge
Some of the content contradicts	and skills for all professional groups working
recommendations earlier in the document e.g.	in outreach services.
universal bereavement training	
I wonder if there should be a recommendation	
that neonatal community outreach nursing	
needs to follow health visiting or district nursing	Thank you for your feedback. The delivery of
with perhaps a module that follows post-	this outreach specific training is outside the
registration specialist training/or runs alongside	scope of this document and will require
it – which could support the skills and	further focus locally and nationally.
knowledge already gained to be adapted to the	
community setting with all the nuances of caring	
for babies and families in their own home	
P36 Data collection and administration	
Each team needs an	
administrator/administrative support to allow	
them to focus on clinical care- not necessarily a	amended
data clerk.	
P37 MDS- should be reviewed e.g. should	
contacts and support needed be a national	
metric rather than type of contact?	Thanks amended
P45 Role descriptor	
This should be reviewed- doesn't leadership and	
governance of services lie with the provider	
organisation? ODNs can guide and support but	
cannot mandate what providers do. What is the	Amended governance to oversight. On site
purpose of on-site presence? Will there be	presence is to foster collaborative working
funding for this role when they are pre-existing	with all outreach teams and gain
high priorities that are not yet funded (Family	understanding of local challenges and
Care, Bereavement and Palliative care)? There	successes.
are lots of positives to such a role, but	Commissioning is out of scope of this
expectations within this that are not achievable.	document



How will the role work with existing ODN leads	
for family experience- care coordinators and	
PFEL?	



Name: Penny Davies	If you are answering on behalf of an organisation please state:
General comments: Can I request that thought is given to using the full professional titles more frequently, for those within the AHP group, within the document, rather than reducing them to the group term AHPs. This would give these professions more equal salience as important contributers to neonatal outreach with other professional groups.	Working Group Response: Thank you for this comment- the MDT working group felt readability was easier using AHP.
Specific comments: Is the information in appendix G appropriately located as an appendix? I would argue that some of this information needs to be included within the main body of the document.	A description of effective feeding is included in readiness for home. More detail is added
	here for reference.



Name: judith angell	If you are answering on behalf of an organisation please state:
General comments: This is great reflecting the philosophy of FiC and outreach. Recognises the different progression points, finances and location of individual services. Inclusion of the MDT is important. Recognising the need to establishing a specialist course to ensure quality and knowledge similar to the neonatal QIS programme would be a useful future goal. Specific comments:	Working Group Response: Thank you for your positive comments. Further attention needs to be given to developing specific courses to support education and training of all outreach staff.



Name: Sarah Brooks	If you are answering on behalf of an organisation please state:
General comments: Fantastic piece of work, so much detail has gone into this, really looking forward to the future of outreach. I have loved reading the information provided by the other services and the examples of good practice.	Working Group Response: Thank you for your positive comments
Specific comments: PG 16 Level 2 Outreach support NAS- 1-2 weekly phone-calls, if baby is on medication would need more face to face. As page 14 suggest this support can be offered by outreach teams operating a robust seven day a week service. I would class this visit as a level 3 to properly assess symptoms and medication management, while supporting those caring for the infant.	The level of care can be individualised and will be dependent on baby and family need and collaborative working with universal services and external agencies. This has been added to the document



Name: Heidi Green	If you are answering on behalf of an organisation places state:
Concrete commenter Deally placed to see this	organisation please state:
General comments: Really pleased to see this	Working Group Response:
publication, well needed. I appreciate the focus	Thank you for these positive comments
on other aspects of outreach role such parental engagement events being included , also	
inclusivity for all babies to have this offer of	
outreach. This is evident in lots of term and late	
preterm infants and families in see in my clinic	
who would benefit from this 'step down' and	
seamless transition to home especially as lower	
gestation and weight.	
Well structured document and all	
encompassing.	
Specific comments:	
I believe workforce calculations should be based	
on average annual admission rate including TC	
with a 20%(for example) increase for community	Workforce recommendations have been
'readmissions'. If robust infant feeding services	modelled on current services that offer
are developing (perhaps another BAPM	equitable access to all levels of outreach care.
workforce standard required) this will see	These workforce figures will need to modelled
reduction in need in physiological jaundice,	and reviewed with robust data collection.
weight loss etc. We would never be able to	
support proposed recommendations for WTE	
nor have enough work for that level of	
workforce.	Workforce structure needs to be determined
I would have liked some more reference to	locally based on the service model and levels
staffing such as minimum of band 7 lead with	of care offered, including the requirement of
band 6 direct support/Senior CNO support -	staff with specialist skill sets. The
other bands after that less relevant unless in	recommendation on individual team structure
level 3 unit or surgical then greater number of	is outside of the scope of this document.
more experienced/Senior CNON needed.	



Cheryl Titherly (she/her) Chief Executive Neonatal Nurses Association

Hello Kate,

A member of ours shared the draft BAPM Outreach Framework with us. We are pleased to see a focus on neonatal outreach service needs. BAPM have created a comprehensive document with powerful parental vignettes.

However, we would like to see the explicit inclusion of complex, term and surgical neonates. The draft currently lacks focus on surgical neonates or term, sick neonates with complex care needs and how the MDT integrated speciality pathways should be imbedded as part of core neonatal outreach MDT care.

The working group strongly recommends outreach services ALL babies and families who have experienced neonatal care have equitable access to outreach services irrespective of any co-morbidities. Those with ongoing medical or surgical needs may need additional support/care packages from other specialists or external agencies – but this is not in place of outreach care rather working together to provide care needs.

The working group have moved away from 'criteria' for outreach instead are recommending equitable access to outreach for ALL babies who have experienced neonatal care. Irrespective of their medical or surgical complexities.

In relation to the workforce, the document poses more questions than answers for services to develop their outreach nursing/ancillary workforce. We'd like to see BAPM make a 'best estimate' of whole time equivalent for case load and include suggestions to pilot with a view to amend the document.

Workforce recommendations have been modelled on current services that offer equitable access to all levels of outreach care. These workforce figures will need to modelled and reviewed with robust data collection. Current data does not support any further workforce recommendations – but with robust national data sets there will be an opportunity to refine this further.

The draft mentions 'registrar'. This role does not exist <u>https://www.rcpch.ac.uk/education-</u> careers/apply-paediatrics/sub-specialties

Amended

It needs to refer to Tier 2/ST 5-7 as outlined in BAPM Optimal arrangements for medical staffing (which you have published for NICU and LNU) <u>https://hubble-live-assets.s3.eu-west</u>



<u>1.amazonaws.com/bapm/file_asset/file/131/Optimal_Arrangement_for_NICUs_revision_10-6-</u> <u>21.pdf</u> Added/amended

On page 28 the level of knowledge and skills are referred to as core, enhanced and advanced. The wording used doesn't seem to fit with the national guidance on enhanced and advanced practice and the examples given should be more explicit using terminology within the existing frameworks, such as the one below by Alison O'Leary. Particularly the limitations within enhanced practice relating to working within dedicated clinical pathways, local protocols and deferring to others for overall plan:

Thank you for this feedback. The knowledge and skills are specific to the whole multi professional outreach service and do not override frameworks such as this which the working group agree should be used when developing role descriptors for outreach roles.



I hope you find our feedback useful.

Many thanks and best wishes for a restful Christmas and New Year



London Neonatal ODN comments:





Stella Rafferty Specialist Societies Co-ordinator

Dear Laura

I am really sorry I missed the deadline. Is it still possible to submit BMFMS feedback on this framework. The comments below are from our RCM rep on the committee:

Just a few comments from the RCM re the Neonatal Outreach Guidance:

 In the information governance section, bullet 4, p.12 - please add midwives to this list. Families are often still under midwifery care at the point of neonatal unit / transitional care discharge (midwifery care may be given up to 6 weeks following birth, although usually 2-4 weeks) There is currently no mention of communication with midwives anywhere in the document, particularly important for the community midwifery teams to have neonatal outreach care plans shared with them if the family are still under maternity services.

Added midwifery services

 p.21 - The first sentence implies that neonatal outreach starts at 6 weeks - needs to be clearer that the variation is the end time for the service. Added text to clarify this point

3. Recommend a more ethnically diverse image on the first page - the majority of BAPM documents seem to feature only white mothers and babies. Thank you for this comment.

Great to see this guidance - definitely much needed. Thanks for your positive comments

Many thanks Stella



SARAH OWENS

Lead Nurse Neonatal Outreach Service

Swansea Bay UHB / Bwrdd Iechyd Prifysgol Bae Abertawe

Please accept the following comments relating to the draft Framework Neonatal Outreach.

We have considered the framework and consulted together in a MDT approach. The team included, Neonatal Consultant, Neonatal outreach nurses, SLT, Psychologist, Physiotherapists, Neonatal discharge liaison nurse, Infant feeding co-ordinator. All professionals have years of experience within neonatology and within offering outreach services, although this is limited for AHP's.

Thank you to your team for reviewing this document

• This guidance is a comprehensive piece of work and it's encouraging to see AHP and Psychology services included and valued. It is important to highlight that no Neonatal unit in Wales meets the BAPM recommended staffing requirement for, AHPs and Psychology, so offering outreach is very challenging, when its offered the time is usually taken from our already underfunded neonatal inpatient service. Hopefully this guidance can guide health boards to consider offering specific funding for outreach in addition to inpatient services (which are already stretched). Likewise within Wales there is no Healthboard offering a 7 day a week service and in Swansea Bay we strive our very best to provide a high quality service to the most vulnerable babies in our community with a very small neonatal outreach nursing team.

• In general we agree and welcome the proposed framework. One area that we strongly disagree with as a multidisciplinary team is the proposed idea of time limiting follow up to 6 months of leaving hospital. As a team providing gold standard care, as per NICE guidelines 2017, we provide follow up until 2 years for all high risk pre-terms. While we appreciate the framework considers all babies who have entered special care and therefore there will be many who will not require such



enhanced follow up, we do not think it good practice to decide a time frame of 6 months to a certain cohort and we feel this point should be considered and that a universal timescale should not be suggested. For example an ex preterm with chronic lung disease still on home oxygen 6 months after discharge would not benefit from a transfer of care to a paediatric team where experience of preterms and weaning of oxygen for chronic lung disease is not their area of expertise. For the sake of a few months this would cause anxiety and likely set-backs for the patient. While we are speaking as an experienced team providing MDT follow up until 2 years with excellent outcomes we also have feedback from veteran parents that have confirmed that they hugely benefit from enhanced neonatal outreach for longer than 6 months, because the neonatal outreach team have specialist expertise with this population and a deeper understanding of their early journey, which is paramount. We ask you to strongly consider if a timescale needs to be included and if so would around the age of 1 year be more appropriate or would you consider a statement of exception within

Thank you for this feedback. The working group felt that neonatal outreach services by definition were to support transition to home and were time limited. The continuation of care under outreach teams is often dictated by available children's community services. However, the working group felt that babies and family's needs beyond 6months of age were in general better met by community teams who are highly skilled in supporting the needs of the complex child. This will of course have local variation, but when commissioning services there needs to be a focus on the early transition to home from neonatal care. As stated, neonatal follow up programme recommendations will continue beyond this age range and is out of the scope of this document.

• From a SLT perspective, within Swansea Bay (and likely in many other areas), there is a group of babies who would benefit from enhanced outreach from SLT to support their feeding development, alongside the Neonatal Outreach Nurses, which would likely prevent longer term feeding difficulties. It is well documented that there is a high prevalence of feeding difficulties amongst preterm babies and those that have spent time on NICU. However, some of these babies do not meet the criteria for specialist core services as they are just below the threshold. For example, an extreme preterm who goes home with NGT and oxygen and is still establishing oral feeding yet does not have a functional swallow difficulty. Also, babies who do have a functional swallow difficulty may wait up to 8 weeks to be seen by core specialist service so bridging this gap with enhanced outreach is so important for our NICU families. Feeding difficulties cause parents/carers high levels of anxiety, effects daily wellbeing and parent-infant relationship and attachment.

This pathway can be developed to meet local need. Standards for dedicated outreach support from AHPs and psychological services are under development by national profession specific groups and is an area for expansion of care as outreach services develop. However, neonatal services should not 'fill gaps' where paediatric services need to develop.



We welcome the introduction of the framework and look forward to seeing the final version this year.

Kind regards

On behalf of the Swansea Bay Neonatal Team

Sarah