British Association of Perinatal Medicine

Neonatal Outreach Service

A BAPM Framework for Practice

May 2025

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Foreword

As a neonatal parent, I felt very privileged to be part of the team in creating a much-needed neonatal outreach framework. Ensuring the best outcomes for families does not stop as the parents leave the life-changing neonatal unit. I was shocked at how much variation there is across hospitals and a lack of understanding as to how valuable neonatal outreach support can be.

When specialist support stops on leaving the neonatal unit parents are often still traumatised and scared to parent their own baby. The transition to home should be a celebrated, happy and well supported moment. I feel this is only possible with the intervention of specialist neonatal outreach services.

I cannot neglect to highlight the sheer number of parental survey responses, 396 families wanted to share their neonatal experiences in support of this work in just a six-week period. This is an overwhelming response from a vulnerable group. Personally, I feel that my baby twins would have benefitted from growing with outreach feeding support, away from some infections that put tiny babies at risk. It could have been the difference between taking both twins home rather than one of my babies. I know that I am not alone in my mental health suffering since and had undiagnosed PTSD for seven years. My story is one of many shared within this framework and behind every parent quote is a precious individual experience. All neonatal families are in desperate need of timely support.

The whole team have strived to ensure this framework is co-produced with parents right from the start, ensuring the parent voice is at the centre. We are now able to focus on delivering personalised care with a flexible outreach service that can fit the ‘actual’, rather than, ‘suspected’ needs of our families. I welcome this framework to guide us as we need to extend the neonatal outreach care into every community.

Emma Johnston, Mum of Jasmin and Morgan, Thames Valley & Wessex Parent & Family Engagement Lead

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Language

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

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Abbreviations

NNOG – Networks Neonatal Outreach Group
BAPM – British Association Perinatal Medicine
NCCR – Neonatal Critical Care Review
GIRFT – Getting It Right First Time
NCOT – Neonatal Community Outreach Team
ICB – Integrated Care Board
GP – General Practitioner
HV – Health Visitor
CPR – Cardio-pulmonary Resuscitation
AHP – Allied Health Professional representing Dietitian, Occupational Therapist, Physiotherapist and Speech and Language Therapist
MDT – Multi Disciplinary Team
NNU – Neonatal Unit
QIS – Qualified in Specialty
WTE – Whole Time Equivalent
SLT – Speech and Language Therapist
NHSE – NHS England
LMNS – Local Maternity and Neonatal System
CPD – Continuous Practice Development

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Summary of recommendations

This is the first detailed publication defining and outlining neonatal outreach services. It offers a future vision of a supportive pathway for babies transitioning from the hospital to home environment. This framework offers multiple new recommendations threaded throughout and there are themes intertwining; therefore, it is essential that it is implemented in its entirety. No subsection can be applied as a standalone concept. Neonatal outreach into the community should not be seen as a separate entity but as part of the continuum of neonatal care delivered across the country.

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.

1. To echo national drivers including the Darzi Report (2024) - Community services need to be more visible and have a higher priority.

2. Neonatal outreach services should be delivered in a psychologically informed and compassionate way, responsive to parent/carer need and feedback.

3. 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.

4. Babies are categorised by level of support need at home, and this level of support may fluctuate during their time under outreach care.

5. Preparing families for transfer to neonatal outreach should begin early in the neonatal journey with the timing of transfer home based on baby and parent readiness.

6. All outreach services should be time limited with pathways for transitioning babies and families to universal and/or paediatric community care within 6 months of leaving hospital.

7. Models of service used should be adaptive to local populations, geographics and cross boundary working in the families' best interests.

8. All Regions/ Networks should have a designated Lead for Outreach Services, and a Senior Team Lead at local level.

9. Outreach workforce recommendations for all professional groups requires further audit, review and development.

10. Staff working in outreach should receive education and training in a specific core set of knowledge and skills and continuing education applicable to their role.

11. National/regional/network data is urgently needed to inform future recommendations of outreach activity and workforce.

12. Future research should be carried out in the field of neonatal outreach and health care outcomes, particularly in new and innovative hospital at home programmes.

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Introduction

Until now, there has been no nationally agreed standards of practice for neonatal outreach services.

The landscape of neonatal care is rapidly changing to meet the needs of families, embedding family integrated care and increasing multi-disciplinary team working, ensuring families are empowered to parent their babies. The parent's voices highlighted throughout this BAPM framework express a need for enhanced support following a stay on the neonatal unit or transitional care. They are experiences taken from the NNOG parent survey (see Appendix A) and it is of paramount importance that these voices are listened to.

"Please make neonatal nurse visits at home mandatory. Outcomes for my twin babies were wholeheartedly improved, as a result of these regular visits. Very difficult for parents going home when they have been almost fully cared for by hospital staff over several months. It's like giving birth all over again - suddenly getting to know your baby and their needs."

There are currently no formalised commissioning pathways for neonatal outreach services. Despite this, national recommendations from the National Critical Care Review (NCCR)[1], British Association of Perinatal Medicine (BAPM)[2], the Three-Year Delivery Plan for Maternity and Neonatal Services[3], the Neonatology – GIRFT Programme National Speciality Report[4], the UK Neonatal Partnership Board[5] and the Neonatal Critical Care Service Specification (NHSE)[6], all highlight a need for a system approach to develop future neonatal outreach and hospital at home services.

The vision is that neonatal outreach services are high quality, accessible, equitable, effective, and work seamlessly across internal and external organisational systems and boundaries, fostering perinatal team working to improve outcomes. Delivering optimum family integrated care (Family Integrated Care – A BAPM Framework for Practice), the patient pathways and models of care will facilitate early transition from a neonatal unit, transitional care or maternity services to continuing supportive care in the home environment with parents as the primary care givers. This ensures no families fall through the gaps of services.

"The outreach team were very supportive and answered all our questions, helped introduce us to the other teams that would be visiting us and managed our expectations of appointments and the process of coming off oxygen."

Scope and purpose

This framework is intended as supportive guidance that defines neonatal outreach service standards and helps to support the development of services at local and regional level. The objective is to promote care to be given safely in the home setting and for families to be the primary care givers in partnership with the neonatal multidisciplinary team.

It aims to:

- provide benchmarking standards for neonatal outreach care.
- be the starting point of the development of neonatal outreach services.
- aid the development of services where they are currently not in place.
- advance existing services to provide hospital at home care.
- to be ambitious for providing future services in the home environment.

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This framework does not intend to include detailed recommendations on the day-to-day running of outreach teams at a local level but includes examples of good practice in the appendices.

The current data and evidence around neonatal outreach are very limited. Where recommendations have been made, these are based on expert experience and opinion and current exemplary practice.

This document is intended to be implemented in its entirety. Leadership and governance are threaded throughout the document, and all would need to be considered when reviewing services. Each chapter is intertwined with one another and cannot be utilised as individual concepts but as part of a holistic framework.

Background

The networks neonatal outreach group (NNOG) have defined a neonatal outreach service as **"**a service delivered by expert multidisciplinary teams of neonatal staff with enhanced skill sets. Delivered over a defined timeframe to empower and support families to provide the ongoing care needs of their baby, offering a seamless transition from hospital care to home and community services."

Neonatal outreach services (also known as Neonatal Community Outreach Teams/NCOT) are in 72% of neonatal units across England, Wales, and Scotland (see Appendix B). All vary in workforce, working models of care, and scope of practice, therefore levels of care to families and service objectives are inequitable and inconsistent.

"Every health professional contradicted each other, and we didn't know what to do for best, we were left alone to search the internet for answers" Taken from a parent who did not receive neonatal outreach care.

"We had a dedicated neonatal team who visited us at home for a few days a week, for several weeks. This was of paramount importance in terms of reassurance and breast-feeding advice. Guidance that was well out of the health visitor or GP remit."

Some neonatal outreach services have advanced to include provision of 'hospital at home' services. This has been defined as "an acute clinical service that takes staff, equipment, technologies, medication, and skills usually provided in hospitals and delivers that hospital care to selected people in their homes"[7]. In the field of neonatology this would typically include short-term nasogastric tube feeding at home, transient home oxygen therapy, and home phototherapy programmes. In some regions outreach services are well established and continually evolving, whilst in other areas there is no provision at all.

Despite delivering some aspects of hospital at home, neonatal outreach teams are operating with limited agreed governance processes and standards. Healthcare organisations are listening to the parent voice and some recommendations have already been made:

- BAPM – All neonatal units should have an outreach service 7 days a week[2].
- Health Innovation North West Coast, North West Neonatal Operational Delivery Network, and Applied Research Collaboration North West Coast – Sustainable investment is required

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to fund safe staffing, digital infrastructure and devices, and governance. Also recommend a co-ordinated approach, sharing best practice, and standardised and quality data collection[8].

- UK Neonatal Partnership Board - Development of neonatal outreach services should accompany neonatal transitional care, to further reduce neonatal unit length of stay and facilitate attachment[5].
- 'Getting it Right First Time (GIRFT) - Expand neonatal outreach services across all neonatal services to support earlier discharge of neonates from neonatal units, transitional care, and postnatal wards. This should include the ability to support short-term nasogastric tube feeding for preterm infants and access to Allied Health Professional (AHP) services. This may require network and commissioning involvement to develop services across the footprint of the network[4].
- Integrated Care Boards (ICB's) – Aim to boost out-of-hospital care and dissolve the historic divide between primary and community services.
- NHSE Neonatal Critical Care Service Specification – Provide community support by an integrated hospital-community neonatal team, with specific training and have competencies and skills for neonatal in/outreach[6].
- Independent Investigation of the National Health Service in England, September 2024 (Darzi Report) - "Community services need to be more visible and have a higher priority given to them" [9].

This new framework offers guidance and support, for the first time, for local care providers, neonatal networks, and commissioners to achieve these recommendations and improve outcomes for families.

Benefits of neonatal outreach services

The evidence around neonatal outreach services is growing (see Appendix A and Appendix C for supportive literature) and there are multiple benefits of neonatal outreach services including:

- Maximising neonatal and postnatal capacity, reducing network transfers.
- Reduces length of stay on the neonatal unit and maternity departments, (such as transitional care).
- Reduction in transfer for preterm babies and the morbidity and mortality associated with transferring preterm infants.
- Minimises inappropriate separation of mother and late preterm baby.
- Meets the requirements of the National Neonatal Unit Service Specification.
- Reduces readmissions in paediatrics A&E, Assessment Units and GP attenders.
- Improves the family experience by reuniting the family unit as early possible, and reducing financial pressure for families (travel expenses, car parking charges, food, accommodation).
- Improves breast feeding rates as mothers are with their babies 24 hours a day.
- Relieving hospital induced psychological pressure and reducing parental anxiety during the time of discharge from hospital.
- Parental mental health support.
- Delivering health promotion advice on subjects such as safe sleeping and car seat safety.
- Linking primary and secondary neonatal and paediatric services.

"Following NICU stay the outreach team have been visiting and are available to answer and queries or questions. The transition home with a baby who has spent time in nicu can be difficult , you worry about the child's health after nicu stay the outreach team are so vital to parents as well as baby it provides security and reassurance that your baby still has clinical oversight to ensure they are reaching their weight etc."

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Principles of leadership and governance of neonatal outreach teams

Leadership in outreach

There should be effective leadership in outreach services to:

- Shape an integrated vision for the development of outreach care.
- Ensure individualised and equitable care.
- Cultivate a culture of safe, compassionate outreach and hospital at home practices.
- Lead innovative and family integrated care practices in the home.
- Harness and embed co-production in shaping services.
- Ensure good communication with stakeholders.
- Promote good team morale.
- Provide comprehensive surveillance of service provision.

To ensure effective networking throughout the region/Network it is recommended that the following leadership structure be in place:

Regional/Network level

- A designated Regional/Network Lead with responsibility for the oversight of neonatal outreach services and this should be included as a workstream in the Network/Regional workplan (see Appendix D for role profile).

Trust/Health Board /System level

- Each outreach service should have a senior team lead at local level (allocated senior lead may be based at different hospital site if using hub and spoke model).
- Each provider Trust/Health Board/system level should have the leadership structure outlined in their standard of practice and service model outline. (Please see Figure1: Neonatal Community Outreach Team Structure in workforce section for details.)

Governance

Neonatal outreach teams can work across traditional organisational and department boundaries providing innovative ways to deliver care in hospital and at home. It is imperative that there are monitoring systems and processes providing assurance of patient safety and quality of care.

- Neonatal outreach services should have defined evidence/best practice-based standards of practice that are in-line with the needs of the baby, parents and/or carers.
- All clinical guidelines for outreach services should follow the neonatal unit protocol of governance (including network guidance particularly if a hub and spoke model).
- All outreach staff should work in accordance with local policies where applicable to their role, i.e. safeguarding, and infection control.
- The neonatal outreach service is part of the wider neonatology workforce. Staff line management should be carried out by the senior outreach team lead who in turn will be line managed by the neonatal unit/paediatric matron at the local or host Trust dependent on service model in place (see service models section).
- There should be a named consultant/nurse consultant (or Advanced Neonatal Nurse Practitioner / specialty doctor (Tier 2) with consultant support) that has dedicated time allocated for oversight of the neonatal outreach service during working hours. For example, Consultant for low dependency area or postnatal ward.
- There should be regular communication (i.e. regular huddles/ ward rounds) between the outreach team leads and other members of the multi-disciplinary team.
- There should be a defined suitable schedule of meetings with the neonatal MDT (including consultant/designated ANNP, psychological professionals, clinical pharmacist and allied

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health professionals) to discuss babies and families in the community.
- Outreach teams should collect data and carry out audits of service delivery (see data section).
- All outreach staff should be working to agreed scope of practice, competencies and educational standards. (see Education and training section)
- Outreach teams should undertake clinical supervision and have opportunities for reflection and professional development.
- Neonatal Networks/Regions should facilitate opportunities for regional mentoring, coaching, peer support and education.

Referral Pathways/Escalation

- Each neonatal unit/service should have referral pathways to escalate medical concerns both in and out of hours.
- Parents/carers should have clear instructions and knowledge on who and when to contact if they have concerns about their baby both in urgent and non-urgent situations.
- Outreach services should have access to specialist knowledge from a pharmacist trained in neonatal care for medication queries and concerns and/or medicines information (MI) service if available.
- Outreach teams should include AHPs and psychological professionals trained in neonatal care. Additional funding should be considered to further develop AHP and psychology services to meet the demand of support required by families as part of the outreach service. In the absence of sufficiently funded services local escalation pathways should be developed.

Information Governance

- Units should ensure that information is available to inform parents of the outreach service and the staff roles.
- All care delivered by the outreach team should be documented in the patients' medical notes, and/or parent medical records where necessary, and any plans of care are communicated with the multidisciplinary team.
- Minimal patient information or confidential notes should be carried with outreach personnel whilst travelling to visits.
- Ideally, all notes should be accessible to other community professionals such as GPs, midwives, Health Visitors and community AHPs.

Reporting

- Each neonatal outreach service should engage in audit, benchmarking and service user feedback to contribute to regional and national data sets (see data section).
- Team leads for outreach should ensure optimal data completeness and effective liaison with the network/regional outreach lead.
- Outreach teams should have a clear line of reporting outlined in standards of practice (may vary due to service model). This should include reporting to provider trusts in-line with individual governance policies and inpatient neonatal services.
- Network/Regional Lead role for neonatal outreach services should report into neonatal network management teams and share practice/guidance with Integrated Care Boards (ICBs) Local Maternity and Neonatal System structures (LMNS's) and Maternity and Neonatal Voices Partnerships (MNVPs).
- Patient and staff safety incidents, (including near misses, medication, system and process incidents) should follow local reporting procedures, and any learning shared through provider trusts, relevant community healthcare provider and network governance procedures.

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Service delivery

Outreach services should not be seen as a separate entity but as part of the continuum of care and an integral part of neonatal services across the country. In the UK there is varied access and a 'postcode lottery' to neonatal outreach care. Where well-established services exist, parental feedback shows improved outcomes and family experience.

"I felt very out of my depth and alone when first at home, I could have done with more care between hospital and home with regards to having had so much monitoring in hospital to nothing at home. My GP was fab noticing post-natal anxiety, but I felt I could've done with specific neonatal care rather than just the health visitor care."

"The outreach team were fab in supporting us during the first few days and weeks. We had some fabulous staff provide advice around baby CPR and recommendations for safe sleeping amongst other things to minimise risks. We were supported with a home visit and text support from the staff which were invaluable."

Service delivery standards

This Framework recommends that when initiated **all** neonatal outreach services should operate a seven-day-a-week service and offer the following fundamental elements of care:

- Support multidisciplinary team planning for transition to home.
- Seamless discharge for complex babies to community children's services.
- Growth & development monitoring and well-being checks (working alongside universal neonatal services).
- Robust parental well-being checks (See Appendix K) and follow-up from appropriately trained staff (including signposting to community mental health services).
- Blood sampling in the home and liaison with the neonatal consultant/family on any care plan changes.
- Infant basic life support training with parents/carers, safe sleep guidance and other health promotions (working in partnership with neonatal unit staff).
- Support of safeguarding needs and liaison with social care.
- Bereavement support (with appropriate training and supervision in place for staff to provide this at a universal level).
- Medicines management.
- Being an advocate for the family between hospital and community health professionals e.g. neonatologist/health visitor.

"The number of appointments we had with different clinics and specialists that meant sometimes multiple trips a week. If these could have been better coordinated and combined then that would have saved us a lot of effort and disruption to getting into a routine once we came home."

In addition, the following components of 'hospital at home' services should be included to reduce parent and baby separation and facilitate early transfer home of preterm babies:

- Transitioning from tube feeding to full oral feeds.
- Transient home oxygen with overnight saturation studies.

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- Babies with specific specialist care needs for example cardiac and surgical babies (unless specialist follow up services exist).

As services develop, further elements of 'hospital at home' are also recommended to be delivered by established outreach services to meet the needs of this unique group of babies and families. These can only be offered by outreach teams operating a **robust** seven-day-a-week service:

- Home phototherapy.
- Home iv antibiotics.
- Babies with Neonatal Abstinence Syndrome: monitoring, weaning medication and symptom support.
- End of Life care support (in support of palliative care services).

Delivery of outreach care in the community

Contacts and translation services

Neonatal outreach services can deliver their support in the community either in a physical, direct face to face way or through other means such as a virtual platform for example video appointments or telephone calls. The style of contact and frequency will depend on baby and family need and will most likely fluctuate during their time under outreach care as parent confidence increases.

Awareness of spoken language and literacy needs is essential and appropriate NHS translation services, support and resources (e.g. using face to face interpreters where possible, telephone interpreting services/interpreting Apps) should be available to all outreach services to ensure safe and effective communication between outreach staff and families. Being aware of levels of digital poverty in the community is imperative so as not to exclude service users from accessing resources or support. Understanding parental communication preferences should guide the choice of contact style.

Direct face-to-face contact

- **Home visits** – Take place in the family home or other allocated home of choice where babies and families can be reviewed, assessed and receive care without the need to attend the hospital.
- **Outreach Nurse Led Clinics** - Multidisciplinary appointments, including AHP, pharmacy and Psychology input, are the gold standard when offering clinic visits to patients. Outreach Nurse Led clinics may also be used to enable the team to see a larger number of babies, and/or the opportunity to relocate clinics away from the hospital environment to limit the possible psychological and stress impact of asking families to travel back to the hospital. (See Appendix E)
- **Peer Support Groups -** Facilitated and organised Outreach Nurse Led Peer support groups can offer an opportunity for monitoring and review of babies and ongoing knowledge and skill sharing, for example talks on weaning preterm babies. These have been highlighted by many parents as a much-valued resource. (See Appendix F).

"More support to create groups for other NICU families to come together and share experiences if they wanted to. I was able to join a therapy group funded by early birth association but if I didn't have that, I think I would have wanted a group of other families that had gone through what we have."

"Really fabulous SCBU meet up once monthly. These would be even better if they were more regular!"

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Non direct contact:

- **Video call** – A virtual call using cameras and current technology to assist with some visual reference during the conversation. This includes NHS approved platforms.
- **Telephone call** – A verbal communication tool to provide immediate contact between outreach services and families. Records of all telephone calls and voice messages should be made in the baby's medical notes including details of relevant clinical information shared as per local standards.
- **Text/WhatsApp and email messaging** – used for non-urgent reminders and/or quick informal communication. To ensure that this type of communication is effective, outreach services must develop practical guidelines on use for staff and parents. Although Text/WhatsApp and email messaging is instant and creates a written communication trail, it should still be used cautiously and not replace more direct methods of communication. It is imperative outreach services refer to local Trust/Health Board communication policies when developing guidelines for staff and parents. They should ensure that hospital technology (i.e. NHS phones and email addresses) is used in all methods of communication with families.
- **MDT Caseload Review –** a regular neonatal MDT meeting to review babies and families under the care of outreach services. This can be an opportunity to review care plans and progress and discuss any concerns with the neonatal team.

Levels of support in the community

When services are well established and with optimum workforce, **every family** can receive outreach support in the form of a 'check-in' telephone call on transitioning home after a neonatal stay (see Appendix G). This support can be increased according to the support and clinical needs of the baby and family.

"Our neonatal unit was amazing, but it would have been really beneficial to us to have even a follow up phone call or something to see how we were getting on."

"I felt worried, and it would have been beneficial to have further support. Neonatal stays regardless of length of time are traumatic and parents need more support to process after."

Historically, access to outreach services has been based predominantly on babies meeting strict medical criteria, together with a degree of professional judgement, as per the requirement for outreach services. 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 for the infant and poorer outcomes for parents and families, particularly in relation to their wellbeing.. The vision for neonatal outreach services is that **all babies and families who have experienced neonatal care have equal access to expert neonatal teams to support the transition from unit to home relative to their need.**

Within the NNOG survey, parents are asking that neonatal outreach services develop further to meet both the medical needs of babies and the specific needs of their families. By categorising babies and families in the community by support or need **'level'** we can tailor individualised care accordingly. Similarly to neonatal in-patient care, outreach support levels can fluctuate. It is anticipated that frequency and intensity levels of contact will reduce over time as clinical care requirements change and parent confidence increases.

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To maintain safety and ensure the needs of babies and families are met when transitioning from hospital to home, we suggest recommendations for the **minimum** support levels for some elements of outreach care. (See Table 1.) Where the baby and/or family have complex needs, which may not be met entirely by the neonatal outreach service, this will require working alongside other agencies and specialised services to ensure all needs are met.

Neonatal guidelines for all elements of care offered by the outreach service should detail **minimum recommendations** for support levels based on workforce and skill mix. This should be standardised across the region/network.

Table 1: Categories of neonatal outreach support level

Category of support level	Description of contact	*Recommendations for minimum support levels
LEVEL ONE **Single telephone contact**	Telephone call check in and single point of contact given to family	ALL babies transitioning to home from neonatal care.
LEVEL TWO **1-2 weekly telephone contact or virtual contact**	Regular contact with outreach team via telephone/online alongside universal community services (HV/CCN)	Growth monitoring, feeding support, infant and parent well-being checks, bereavement support, safeguarding, Neonatal Abstinence Syndrome
LEVEL THREE **1-2 weekly face to face contact with telephone contact**	Regular face to face contact via home visits/ clinic may include additional telephone support and AHP, pharmacy and psychology support	Home oxygen, short term tube feeding, blood sampling, stoma care, wound care
LEVEL FOUR **3 times a week to daily face to face visits**	Frequent to daily face to face contact. This will include complex babies & Hospital at Home care with AHPPP coordinated contact as required	Home Phototherapy, home iv antibiotics, complex babies

***Please note** this is the **minimum** level of support required for safety- individualised care may require more intensive support.

These care levels can be used to audit caseload complexity and alongside further data collection (see Data section) support service/workforce development and support commissioning of outreach services.

The support level required will depend on when in the neonatal journey the family go home, whether they have additional medical needs, the emotional impact of their neonatal journey and their support network at home. Making the decision of when babies and families are ready to go home is complex and multi-faceted.

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Readiness to transition to outreach care

"It felt a bit like we were rushed out of neonatal in the end. We didn't feel quite ready and didn't really know where to turn for advice."

Assessing physical, emotional, social and parental readiness for transition to outreach care is an important part of the discharge process and being well planned is less stressful for the family. The outreach team should have a presence on the neonatal unit and be part of the team guiding parents through the transition process to home. The neonatal outreach team should be introduced to the families as early as possible on the neonatal journey.

"It would've been good for someone to be on hand to talk to when being told about discharge to discuss any worries/fears as I was really upset and overwhelmed bringing her home. Someone to talk through that experience with would've been beneficial."

In assessing readiness for transition home to the outreach service there are multiple factors for consideration. These should be discussed with the full MDT including parents to ensure a safe transfer:

- **Physiological Stability –** Babies should maintain body temperature in open cot, have a stable and positive growth trajectory, show no significant infection markers, apnoea, bradycardias or desaturations for 48 hours.
- **Self-ventilating** - in ambient air or with a plan for low flow oxygen at home.
- **Feeding effectively - Feeding by breast and/or bottle in response to feeding cues at regular intervals throughout the day** for 48 to 72 hours prior to transfer home. This can include top ups by nasogastric tube. Parents should be confident in assessing feeding effectiveness using appropriate feeding assessment tools (see Appendix G for guidance on effective feeding and feeding assessment tools).
- **Parents integrated in care and relevant knowledge and skills frameworks completed** – including medication counselling and parent drug information resources (eg Paddington medicine information).
- **Psychological barriers to discharge and sources of support identified –** whilst the transition home is likely to be an anxiety provoking time for many families, every attempt should be made to ensure families feel psychologically supported during this time.

"From ventilator to home with no support in less than a week is a lot to get your head around."

Babies with complex needs and/or requiring 'hospital at home' services will require additional individualised assessment, relevant parent/carer knowledge and skills frameworks completed and/or equipment that may include:

- **Nasogastric Tube Feeding.**
- **Phototherapy support.**
- **Respiratory support.**
- **Specialist referrals for ongoing care** - Liaison with neonatal/paediatric AHPs, diagnosis-specific specialist nurses/teams, psychology, the paediatric acute and/or community team.

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Supporting families through the transition to home process

"It's a very strange transition going home after spending so long in hospital. As much as you want to be home, it takes a lot to adjust to especially with oxygen/ feeding tubes it can feel daunting."

Neonatal professionals should sensitively help to prepare families for transition home from admission (see Appendix G). Empowering parents/carers and providing information and education that is timely and spread out to support parents during this transition[10].

We recommend:

- Good communication between the outreach service, the multi-disciplinary team, and the parents tailored to the individualised needs of the families.
- A neonatal outreach team presence on the neonatal unit and transitional care.
- Consideration to the language and cognitive ability of the family ensuring information is presented clearly and can be easily understood.
- Opportunities for families to meet the outreach service and ask any questions regarding care at home for their baby.
- Written/multimedia information given about the neonatal outreach service and how to contact them, along with written information relevant for any medical needs for their baby.
- Introductions made to the wider team to the family where possible.
- Parents hold relevant information about their baby's neonatal stay including discharge summaries, and universal services parent held records are completed.
- Individualised care plans for each family prior to hospital discharge. To include information on frequency of contact, what to expect on home visits, access to out of hours medical support, and information on how the neonatal outreach team will work alongside universal services.
- Robust knowledge and skills frameworks/competencies and education, developed collaboratively across the network, to empower parents to feel confident with their babies care and how to troubleshoot.
- Opportunity to room in either in the neonatal unit or transitional care prior to transitioning home.

Supporting the families' mental health

"I hadn't processed our journey at discharge and didn't realise the impact this would have on me once I got home."

Neonatal outreach teams play a vital role in supporting the mental health of parents during the transition to home. "Parents with a premature baby are **50% more likely to experience psychological distress** compared with parents who do not spend time on the unit" [11]. It is widely reported that parents whose baby has a neonatal stay are more at risk of developing or worsening mental health conditions[12] and parents often do not experience these changes in mental health until after the baby is discharged. Specialist psychological support, provided by trained psychological professionals expert in neonatal care, should be prioritised for families within outreach settings.

In the NNOG parent survey (see Appendix A) despite not being asked directly about mental health

experiences, 94 (23%) of responders cited a need for mental health support with eight responders mentioned experiencing PTSD or trauma due to their neonatal admission.

"I felt like once we were home, we were alone, I was only young and it was terrifying, so much so I developed mental health problems."

"As a result of my twin boys being in NICU for 12 weeks I developed PTSD and really struggled to cope. I needed more support with my own mental health and how to deal with the trauma of NICU."

"It was incredibly scary… I felt very alone, no one understood the stress after NICU. My HV only came because I had PTSD and suffered a bereavement."

Neonatal outreach teams should have enhanced skills and knowledge to recognise and signpost for mental health concerns in the family (see education section).

Safeguarding families and staff

Safeguarding is an integral part of the outreach service, this requires effective communication between unit, outreach and community teams/agencies of any safeguarding aspects. Outreach teams provide additional support for vulnerable families and help to safeguard infants and their families. They work alongside universal services and will forge close links with social services.

Outreach staff have a responsibility to safeguard all children and vulnerable people in the family's home. It is essential that they follow local safeguarding policies and care pathways. Policies should also be in place to ensure the safety of the outreach team, particularly when visiting homes and travelling in the community [13]. These should include:

- All staff carrying a mobile phone and be contactable when off hospital site.
- Limiting home/clinic visits after dark.
- Systems are in place for the team lead to know staff locations/addresses when off hospital site.
- When teams are using their own cars to travel, they are well maintained and have breakdown cover.
- Arranging joint visits with other healthcare professionals when there is a potential or known risk.
- Ensuring lone working policies are in place and all team members have lone worker safety equipment (such as personal alarms).
- Risk assessments and action plans are in place for any work activities that could present a risk to health or personal safety when at work.
- Robust reporting pathways for any personal safety 'near misses' or incidents.

Capacity of outreach service

Due to the lack of previous standards for neonatal outreach services, individual families having different levels of support need, and with very limited data, it is currently impossible to quantify a maximum capacity of caseload for outreach services. However, it is anticipated that with further data collection (see data section) on referral patterns, outreach caseload intensity and support needs at each level it will be possible to develop 'safe caseload numbers' in the future.

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All services should:

- Ensure there is adequate staffing levels to meet the demands of the service (see Workforce section).
- Prioritise resource allocation depending on severity and support needs of families and babies in the caseload.
- Consider alternative time-saving methods of delivering contact to families including phone call, video call and outreach clinics when appropriate.

Geographical areas

90% of neonatal outreach services in the UK have a defined geographical area of coverage, although 44% have reported that they travel outside of this area (see Appendix B). This is due to there being vast areas of the country with no outreach service cover. Babies may be cared for in a neonatal unit or transitional care in one region and then discharged to a home address within another. Families may also need to receive specialist follow up from a tertiary neonatal unit but have a home address in another region therefore the hospital base of the outreach care will differ. Neonatal outreach services should be commissioned to work flexibly to accommodate these needs and ensure families are given equity of service irrespective of their postcode.

"There were some issues with working out who would be providing our care as baby was born in one county but we lived in another county (boundary lines) and this was hard as we would have preferred to have stayed with the county that the baby was born in for continuity of care and support instead of being transferred where we had to explain our baby's story to each new team."

We recommend that the **regional/network outreach leads** (see Leadership section) for outreach have an awareness of:

- Geographical boundaries of all outreach services.
- The need to review geographical boundaries on development of new outreach services.
- Any gaps in service or overlapping areas of cover that may occur.

The regional/network outreach leads will work on the expansion of neonatal outreach services, and with further coverage should be limiting the travel time to under 45 mins if possible. Care should be transferred to the most local outreach service to the family's home address.

"We had left a neonatal unit that had a lot of expertise and when going home. We felt like we had lost all this expertise, and no one seemed to specialise in extremely premature babies. It seems dependant on area as to how much support there is on offer."

Resources for an outreach service

The resources currently available for outreach services varies greatly (see Appendix B). To provide a high quality, effective outreach service that is accessible to parents, teams should have access to:

- Landline and mobile phones.
- Lone working devices.
- Information technology equipment.
- Car (can be own transport with business insurance or hospital lease/pool car).
- Satellite-Navigation system (on phone/in car) or area map.
- Clinical resources, i.e. nasogastric tubes, weighing scales, length mats, blood-taking equipment and specialist resources as required.

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Transitioning from neonatal outreach services

"It was a scary journey, especially coming home with oxygen. The Outreach team made us feel so comfortable on their visits out to us, and even when we were transferred to the care of the community nursing team we still felt so comfortable."

Neonatal outreach services deliver support over a 'defined timeframe' but up until now this timeframe has been variable from as short as 6 weeks after leaving hospital to up to 2 years after transitioning home. As neonates mature and families are settled in their home environment the support needs of the family will change. By 6 months of leaving the neonatal unit the on-going needs of babies and families may be best met by paediatric trained staff.

Families should be empowered to be part of the decision-making process on the best timing of full transfer of care to the paediatric community nursing teams or universal services. This transfer of care may be made relatively quickly or over a period of a few weeks' dependant on the family's needs. By assessing the needs of the family regularly the appropriate expert professionals can give support tailored to individual family's on-going needs. The aim of which, should be to provide a smooth transition to a longer-term support network in a timely way.

Neonatal outreach services can signpost and work alongside specialist services for any infants known to require additional care in the community and assist in smoothing the transition process for these families. They should help families to get to know their longer-term support network and ensure families build relationships early on with health visitors, GPs, Community AHPs, community nursing teams, psychology professionals and/or social workers.

We recommend that neonatal outreach services:

- Ensure families are fully supported by universal services and transitioned to any relevant required paediatric community services by **6 months post transfer from hospital to home.**
- Deliver parent skills/ information/knowledge alongside health visitor and other community professionals to empower parents to care for their infant at home.
- Include the local care pathway for babies transitioning from the outreach service in their local guidelines/standards of practice.
- Have an awareness of support networks available for families in their local area and build strong relationships with providers.

"We didn't have support from family or friends and felt extremely lonely and anxious once baby was off oxygen and the 2x weekly visits from neonatal outreach stopped."

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Service models

Outreach service models will vary and adaptability over service model needs to be considered, as the service must be suitable for the needs of the local population and geographical area. However, all neonatal outreach services should be:

- Responsive to parent and family needs and feedback.
- Staffed by a multi-disciplinary expert team (see workforce section).
- Operate a seven-day-a-week service. Hours of operation to be determined by local need and service model.
- Accessible; considering all vulnerabilities, marginalised families and individual need such as language, literacy, digital poverty and physical access.
- Flexible.
- Inclusive.
- Seamless, working collaboratively with primary and other secondary care services.

Neonatal outreach services should complement and not replace any universal service (including health visiting or primary care services). It should be acknowledged that health visitors and GPs require enhanced knowledge and skills in the care of babies and families who have experienced neonatal care. Working alongside neonatal outreach teams in supporting families after leaving hospital is an effective way of upskilling in this area of healthcare.

"We were fully supported by our local midwife and health visitor, and outreach team."

"Had support from perinatal team and HV teams but didn't feel that they were much suited to support a family of a baby who had either been premature and/or in NICU - it felt like they had no clue what to do."

Regardless of the service model implemented neonatal outreach teams should maintain a presence on the NNU. Research and parent experience shows that support from familiar staff aids transition to home[14].

"It was all arranged very well and we had made great connections with all the professionals in my son's life. They were always happy to see us and very supportive when I felt something wasn't right with my son. For the first two years we were very well supported and had good support after then. We also had had the same professionals in my son's life from the beginning so they know my son well. We feel very lucky to have had what we have through the NHS."

All service models must follow a collaborative approach between families, nursing staff (Outreach and NNU), AHPs, psychological professionals, pharmacists and medical staff. The core team in each model will be the outreach nursing staff who will work with the specialist arms of neonatal medical and AHP, psychology and pharmacy staff in supporting the families in the transition to home. (See Appendix J for details of AHP and psychological professionals.)

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- Nursing staffing for outreach should be drawn from experienced staff who may have hybrid roles across hospital and community care dependant on the chosen service modelling. Staff who bring additional skills sets (e.g. infant feeding) to outreach teams will have beneficial impact on families. In each service model, oversight of nurse staffing and potential impact of unit cot capacity by delivering hospital at home services will need to be evaluated.
- In larger experienced outreach services, career pathways should be open for developmental roles for non-QIS experienced nurses or midwives skilled in community care to specialise in neonatal outreach services and undertake QIS training.
- There should be a named consultant/nurse consultant (or Advanced Neonatal Nurse Practitioner/speciality doctor (Tier 2) with consultant support) that has dedicated time allocated for oversight of the neonatal outreach service during working hours.
- With the current limited AHP, pharmacy & psychology availability across UK neonatal units, support may come from NNU AHP/pharmacy/psychological professionals or community AHP/ psychological professionals depending on available resource, service model and funding. Some outreach service models may need support to ensure adequate access to AHP/pharmacy/psychology input is in place and this should not be at the expense of often already limited inpatient services rather from additional resource. Coordination with operational or clinical networks or via Local Maternity and Neonatal Systems can help to identify gaps in staffing requirement, knowledge and skills. [1,4,6].
- Gaps in staffing neonatal outreach services (all disciplines) should be highlighted on relevant risk registers.
- All service models will require strategic leadership and administrative support.

One size does not fit all, recognising this, this framework considers three different service models to meet these needs. Dependant on geographical area and funding it may be appropriate to have a combination of individual and hub and spoke service models across a regional footprint. When setting up or expanding services it is essential to undertake equality impact assessment in line with local policies to ensure the needs of all service users have access to tailored outreach support.

See Appendix H For practice examples of the three different service models in place across the UK.

Individual Trust outreach services

The individual in-house outreach services will support the transition to home of infants from the neonatal unit for the provider trust catchment area.

Hub & Spoke outreach service model

A hub and spoke model in healthcare has one centre as the hub which receives the funding and supplies most of the intensive services and the other centres are the spokes which offer more limited services and refer into the hub[1]. However, with neonatal outreach the model provides equity of service between all centres in the model. One neonatal service will be the hub, and the other services within the model will be the spokes. There will be a service level agreement between all provider Trusts involved. The outreach team may see babies transferred home from any of the neonatal services involved. Medical responsibility, MDT support and follow-up should be arranged with the family's local neonatal unit. This model needs careful planning and coordination for appropriate funding, contracts and governance.

LMNS Hub and spoke outreach service model

This model is a hub and spoke model covering an LMNS geographical footprint providing services to all units within the LMNS. There is a generally a single host (hub)with multiple local spokes. Patient pathways, governance and reporting processes are set across the LMNS with local collaborative working established.

Network/Regional Hub & spoke outreach service model

This model is a hub and spoke model covering a much wider geographical footprint and providing services to many units. It may require more than one host (hub) depending on geography and services offered. This service model may benefit from the recruitment of designated outreach allied health & psychological professionals. Strategy, leadership and administration will be significant to ensure operational excellence.

Careful consideration is needed to determine which model or combination of models best meets local family need. The table below considers the benefits and drawbacks of each service model to help inform choice.

Table 2: Strengths and Challenges of Outreach Service Models

Individual Trust outreach services

Pros	Cons
• **Direct oversight**, enabling a tailored approach for local requirements. • **Closer integration** with other trust services. • Ability to be **flexible** and adapt quickly to changing circumstances. • **Internal governance**, 1 trust process for Information Technology and Human Resources. • **Close liaison** with neonatal MDT. • Ability to provide **in-reach support** and **discharge planning** on the NNU/TC. • Single **physical base.** • Ability to provide **dual roles** (working on neonatal unit and outreach).	• Limitation in **ability to scale service**. • **Limited resources**, particularly with regards to staffing. • **Reduced team resilience**. • **Geographical limitations** may prevent support to families outside of Trust's geographical boundaries. • No **information sharing agreement** with neighbouring trusts, if required. • No **benchmarking, external collaboration or shared resources (if no Network/Regional engagement).** • **Variability in care across a region/ Network.**

LMNS/System Hub & Spoke Model

Pros	Cons
• **Sharing of resources and expertise**. • **Enhanced team resilience** - to maintain and equal and consistent service. • **Enhanced succession planning and career pathways.** • **Consistency of standards** of care and guidelines ○ **Shared governance** and reporting structures. • **Supports smaller services** in being able to offer outreach care, enabling access for all, reducing staff isolation. • **Shared practice, training and learning opportunities**.	• Requires **time, coordination and communication** between all trusts. • Needs **hosting organisation.** • Need to ensure lead nurse for the service in the hub is able to **support and manage** all members of the team in all sites. • Complexities of **cross boundary communication**. Outreach team need to identify & liaise with appropriate neonatal MDT accordingly. • Consideration of **individual unit guidelines** within hub & spoke model. • **Efficiency of service** for multiple site working- travelling/parking/ office space

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• **Information sharing agreement** & standardised **data** collection & reporting. • Streamlined **commissioning** structure. • Shared **safeguarding** and **clinical supervision processes**.	etc. • **Multiple Trust processes** for Information Technology and Human Resources. • **Variability in care across a region/Network.**

Network/Regional Hub & Spoke Model

Pros	Cons
• **Enhanced LMNS service model benefits** in regards to: ➢ Developing **standardised resources and guidelines improving consistency.** ➢ Developing **expert outreach teams** inc MDT. ➢ **Streamlined communication.** ➢ **Region/Network wide standardised care**. ➢ **Access to all** – region/network wide.	• **Intensified LMNS** service model challenges • Highly complex operational processes in regards to: ➢ Hosting organisation(s). ➢ Multiple site working. ➢ IT systems. ➢ honorary contracts/ service level agreements. • Variability in care nationally.

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Education and training

It is essential to recognise that the role of outreach nursing staff is different to acute unit-based care and requires additional knowledge and skills/competencies. The required level of each individual team member's education will be driven by the needs of the family and dependant on role within the team.

Professionals who provide services to neonates and their families transitioning to home require a highly complex set of skills including enhanced assessment, observation, intervention, evaluation and interpretation of findings for the preterm and high-risk population in the home setting. This includes clinical training and expertise in the neonatal setting and sound theoretical and evidenced based knowledge underpinning practice[6,16,17],.

Education and training

- All staff working in neonatal outreach teams are required to develop a core set of knowledge and skills applicable to the job role (Table 3).
- In addition to this core knowledge and skill set, further education and training is required to build enhanced and advanced clinical and non-clinical knowledge and skills to ensure the delivery of safe, evidenced based, high-quality care that meets the needs of families and babies [6] (see Table 3).
- Neonatal outreach teams must have robust induction programmes for staff new to outreach working. This should include a knowledge and skills framework with specific competencies for completion during an induction period.
- It is paramount that all health care professionals delivering outreach care work within their level of competency and expertise and recognise when to seek advice/support from other experts and/or specialist services.
- In supporting the baby and family with the transition to home, and in preparation for lives beyond the neonatal unit, all outreach staff are provided training in psychologically informed care. This will include communication, understanding and responding to distress (particularly recognising signs of trauma, PTSD, bereavement support, attachment concerns and health related anxiety), relationship building, collaborative working, compassionate helping and facilitating positive attachments.
- It may be beneficial for outreach teams to have designated individuals, with enhanced skill sets, to work closely with the neonatal unit specialist link roles (see Table 3).
- All professionals supporting/advising on neonatal outreach care should have:
    - a comprehensive understanding of the principles of neonatal care
    - Undertaken profession specific neonatal training and education to enhance their knowledge and skills in their area of clinical expertise.
    - meet profession specific competencies for outreach care, where these exist
    - be able to apply this knowledge base to optimise outcomes in neonatal outreach.

Maintaining knowledge, skills and competencies

- Education and training must be set as a rolling programme with planned annual update days relevant to neonatal outreach care.
- Training needs of individual staff members should be identified at induction and in annual reviews and appropriate CPD opportunities supported.
- Accessing the following CPD opportunities will benefit maintaining and enhancing knowledge and skills in neonatal care.
    - Undertaking shifts on the neonatal unit, transitional care depending on staff competencies.

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- Attending expert education sessions (e.g. training from AHPs, Pharmacy and Psychology).
- Shadowing neonatal staff or other neonatal outreach teams.
- Work shadowing specific professional experts e.g. discharge planning nurse, AHPs, pharmacists, community midwives and children's services.
- Shared learning with paediatric community nursing teams.
- Shared learning opportunities with outreach services across networks/regions and nationally (see Appendix I).

Education of others

Neonatal outreach teams hold the responsibility of promoting their services, ensuring that unit staff and families have a comprehensive understanding of outreach service delivery. This has the benefit of supporting families as they enter the transition to home programme and ensuring neonatal outreach becomes an embedded part of the neonatal journey.

Unit and community staff's CPD can be enhanced by offering the opportunity to shadow outreach teams. Outreach teams can also be considered as a student placement.

Outreach teams support the education and training of multidisciplinary team(s) providing ongoing advice and expert resources for all disciplines where neonates have longer term needs which will require transitioning to children's community services, to ensure the specific needs of the preterm baby are recognised and identified.

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Table 3: Knowledge and skills for neonatal outreach staff

Core knowledge and skills **ALL outreach staff in context of individual roles**	**Enhanced** **As core plus below (Registered nurse)**	**Advanced** **As core and enhanced plus below (Lead outreach nurse)**	**Designated roles**
Experience of working within neonatal acute care	Neonatal QIS	Leadership /governance	Educator
Foundation Course/unit/profession specific competencies	Advanced Safeguarding	Data management	Infant Feeding
Basic awareness of feeding development and identification of onward referral	Education/teaching experience		Safeguarding
Growth monitoring and interpretation	Critical thinking and problem solving	Psychological safety in teams Creating high functioning/ compassionate teams	Phototherapy
Psychologically informed care including communication, relationship building, collaborative working and attachment	Taking & interpreting blood samples		Home Oxygen Therapy
Basic neonatal life support	Audit		Professional Nurse Advocate
Bereavement support and Palliative Care Training	Non-medical prescribing		Bereavement & Palliative Care
Recognising deteriorating baby	Mentoring/supervision		Surgical/ cardiac/ complex needs specialists (depending on needs of service)
Safeguarding in the community setting	Cannulation & administering IV antibiotics		
Collaborative MDT working, including an understanding of care offered by community children's and family services	Prescribing / advising on phototherapy/ oxygen therapy		
Lone working, personal safety and conflict resolution	SIM compassionate communication skills training		
Basic awareness of core child development milestones and movement patterns			

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Recommendations

1. All outreach services must develop robust induction programmes at unit, system or network/regional level.
2. Network/ Regional Education Leads work collaboratively with Network/ Regional Outreach leads and Outreach Teams to develop standardised training programmes making efficient use of the available subject experts to deliver core and enhanced education and training across the wider system.
3. Explore opportunities with HEIs to develop courses and competency frameworks to meet the specific training needs for the specialist outreach workforce.
4. Adequate funding and study leave should be made available for education/ training/CPD in the development of neonatal outreach services.

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Description and structure of workforce

Introduction

Having the right people with the right skills, in the right numbers and at the right time is integral to the delivery of high-quality care [18]. This is as true within the context of neonatal outreach as in any other area of health care.

Describing the scope of practice and workforce required to provide these outreach services is fundamental to the successful delivery of high-quality care beyond the neonatal unit.

"Without the outreach team we would have been lost on a journey we were already finding so hard to navigate."

Standards for neonatal staffing requirements within in-hospital neonatal care have been developed[19,20,21,22,23,24,25,26,27]. There are limited staffing standards for outreach and follow-up services currently in operation. Psychology have developed neonatal specific recommendations for follow up and support during transition from hospital to home, with those staffing requirements focussed on the AHP professions under development.

In the absence of much formal evidence on which to base workforce requirements for neonatal outreach services, the following recommendations for staff should be considered to establish an outreach service 7 days a week capable of providing all recommended aspects of care. The process will be iterative. Audit will be undertaken, and the findings of the audit used to make further recommendations for the services.

Currently many neonatal outreach services and early discharge programmes have not been formally commissioned. Teams have grown by utilising neonatal budgets where there has been capacity. It is acknowledged that further investment may be required to meet these outreach staffing recommendations.

Neonatal Community Outreach Team Structure

The structure of the outreach team may vary according to the model of care used to deliver the service (See Appendix H for current practice examples).

The skills required within the team are the same for any outreach service, although the whole time equivalent (WTE) hours required might vary depending on the size of the service (both in respect of patient numbers and geographically) and/or the way the service is delivered. The recommended structure of the team is summarised in Figure 1.

N.B: All staff - nursing, medical, ANNP, AHP, psychology and pharmacy - working within the outreach team must be appropriately trained in neonatal outreach (see education section).

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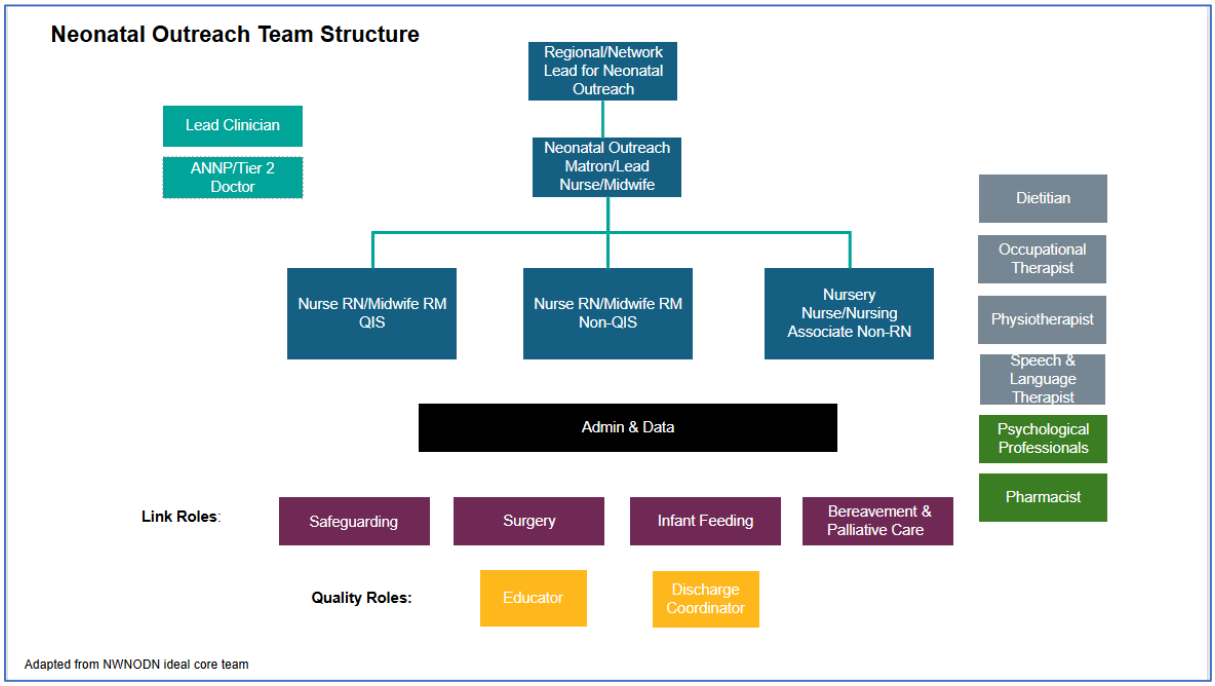
Figure 1: Neonatal Community Outreach Team Structure.



Nursing workforce

The team should consist of registered nurses, (including career pathways for both Qualified in Specialty (QIS) and non-QIS) and non-registered nursing staff (nursery nurses, Nursing Associates). In addition, there must be a Lead Nurse for Outreach at service level. It is recommended that there is someone identified within each Region/ Neonatal Network with oversight of Neonatal Outreach services, however, this role may be delivered in different ways in each Region/ Network (see Appendix D for role descriptor).

Nursing workforce roles are not described in terms of salary banding (i.e., band 4, 5, 6 etc) because it is acknowledged that these vary between local Trusts/Health Boards. It is recommended that national role descriptions are developed to support consistency in the requirements of each role across the country and the writing of job descriptions and person specifications at Trust level. It is expected that this will subsequently achieve more consistency in the banding of roles.

It is essential that there is a clear organisational structure included in job descriptions and an explicit process for escalation for all staff to follow when they encounter circumstances that fall outside the remit and responsibilities of their role.

The skill mix of the nursing team should be established locally to reflect the needs of the babies being cared for in the community the service covers. The WTE required at different skill levels may vary between services dependant on the service models used.

It was not considered necessary to have a neonatal educator as part of the outreach structure. However, time should be allocated within each role description to ensure neonatal outreach specific education can be delivered by appropriate expert staff including experienced neonatal AHPs and psychology professionals, and all members of the team can attend regular education and training updates and meet the mandatory training requirements of their employing Trust (see education section).

Additional quality and link roles such as infant feeding, surgery, safeguarding, tissue viability etc. should be available to provide specialist advice to the outreach team when required.

Network/regional leads should support signposting to specialist services within regions.

Identified roles, for example infant feeding, may be included as a part of team structure depending on local service need. As the NNOG survey has highlighted, fifty (12%) who responded to the NNOG survey said they had a need for more support with infant feeding, with an emphasis on breast feeding support.

"Asked several times to see the breastfeeding specialist as I was struggling so much with expressing/trying to feed and it took nearly a week for her to come by which time I'd given up as I was in so much pain and baby was by now settled on bottle feeds.....you feel even more of a failure as not only have you not kept your baby safe, you also can't do the most basic of tasks."

"I wish I had more support with breastfeeding. I turned to expressing and feeding through a bottle but with the stress of her weight loss and my mental health from everything we'd been through my supply started to go."

Medical workforce

The first line of escalation for clinical advice and support for outreach services could be provided by an **appropriately trained** ANNP/ Registrar and/or Nurse Consultant/ Consultant.

There must be a Neonatal/Paediatric Consultant identified as the lead clinician for the outreach service with identified PA time to fulfil the role.

The number and nature of contacts between babies and families (receiving outreach care) and medical staff will need to be captured so that any additional medical time required for outreach can be evidenced and resourced appropriately.

AHP and pharmacy workforce

National standards for in-hospital neonatal AHP, psychology and pharmacy workforce have been developed and published[22,23,24,25,26]. However, many neonatal services have yet to meet these standards, either due to a lack of funding and/or availability of suitably trained staff. Even in those areas where staffing recommendations are met there is insufficient capacity to take on the additional work required for outreach.

Urgent focus must be given to fully establishing acute unit AHP and pharmacy workforce to ensure optimum support in reaching baby and parent readiness for transition home. Any impact of a fully established in-hospital AHP team, must be evaluated, as this may change the AHP need in the community setting. Until sufficient AHP workforce is established support from these clinical experts for babies and families under the care of outreach teams will be severely limited. AHP services must be included in business case development and grow concurrently with outreach nursing teams.

"The community nursing team, dietitian, SALT and oxygen nurse were all really good."

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Psychological professionals

Preliminary data suggests that the demand for psychology within outreach teams will be significant and should be developed in conjunction with in-hospital services[12]. This is because for many parents, whilst initial psychological work can begin whilst they are on the unit, due to the nature of trauma processing, this work is often requested by parents when they are more able to process the experience at home.

"As a result of my twin boys being in NICU for 12 weeks I developed PTSD and really struggled to cope. I needed more support with my own mental health and how to deal with the trauma of NICU."

"Their support, guidance and care have been so appreciated. In the unit counsellors and psychologists were available to parents but this support had not been continued. I feel it would benefit parents to have opportunities for group or individual sessions with a counsellor or psychologist."

It is essential that there is designated, funded time for AHP, psychology and pharmacy roles within outreach teams. Discussion at local level is crucial to ensure that additional funding for AHP, psychology and pharmacy services in outreach teams is included early in service development and planning.

See Appendix J for examples of best practice examples and contribution to outreach care by AHPs and Psychology.

Data collection and administrative roles

Accurate and timely data collection will be essential to identifying the outreach services required across an area, establishing appropriately resourced services and monitoring service delivery and quality outcomes. Therefore, an administrator/administrative assistant will be integral to the team.

All clinical staff must have time allocated within their workplan for administrative duties.

Calculating workforce requirements for outreach services

Nursing Workforce

A literature review of workforce standards in community settings across any specific healthcare population, such as paediatrics or District nursing, revealed no single method for calculating community nurse staffing requirements[27,28].

Outreach services will provide care to neonatal babies and their families across a defined geographical area. The number of contacts made by any single service will vary according to many factors such as the birth rate, size of local maternity and neonatal services, support need, geography of the area and local socio-economic factors.

Although rural areas required travel across greater distances, journeys within towns and cities were often protracted during peak commuter travel times. Most regions were reporting travel times that did not exceed one hour (except when local travel is disrupted). This has been used as the basis of travel assumptions for the purposes of calculating workforce requirements.

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In the absence of any established method for calculating staffing standards for outreach, the group agreed to model nursing workforce requirements using examples of good practice and based on the live birth rate, the number of referrals into outreach (rather than admissions to the neonatal unit) and existing WTE workforce providing the service to that population. This calculation would enable a 7 day a week service to deliver the fundamental elements of outreach and hospital at home services (See Service delivery section) This potentially includes caring for babies on home phototherapy referred directly from maternity and for babies discharged to a different postcode to their referring hospital.

- **Using this approach, a recommendation of one WTE member of nursing workforce per 800 live births was established to deliver all aspects of neonatal outreach care.** The lead Neonatal Outreach Nurse role must be additional to this.

Within the timeframe to produce this document it has not been possible to test this modelling across all existing outreach services or to forecast what would be required in areas where outreach services have not been established yet. A necessary part of developing the recommendations further would be to test them across existing outreach services and model them for areas where services are not currently in place.

Medical workforce

- Medical workforce hours for ANNP and Lead Consultant time will need to be assessed and tested. Medical workforce requirements within Paediatric community services may provide a steer for this.

AHP and Pharmacy workforce

- There is currently limited data on which to base staffing recommendations for AHP and Pharmacy staff groups. Requirements for AHP and pharmacy outreach provision are currently being considered based on existing demand, expert experience and benchmarking examples of good practice where they are available. Professional groups are using this data to develop and publish proposed staffing recommendations which will provide a safe and high-quality service to babies and families transitioning from hospital to home. It is recommended once published these staffing recommendations are used to establish dedicated expert AHP workforce to support outreach services. AHP and pharmacy staffing models would need to be trialled and audited to ensure demand for services is met.

Psychological Professionals workforce

- Psychological professional staffing standards for outreach and follow-up have been developed[29] (see Appendix L for summary table). This has involved close liaison with perinatal and maternal mental health teams nationally to understand eligibility of neonatal families for these services and the needs gap based on the evidence base. Workforce modelling for these services is based on the psychological workforce establishment in other NICE compliant paediatric disciplines. The demand for psychology within outreach teams will be significant and should be developed in conjunction with in-hospital services.

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Summary

- The structure of a neonatal outreach team is described.
- Making robust, evidence-based recommendations for the WTE hours required for all outreach roles will take more time and will be an iterative process as neonatal in-hospital and outreach services develop.
- Outreach services that meet the recommendations are likely to be established incrementally as services are established, evolve, and funding is made available to meet demand.

Recommendations for workforce

1. Audit the recommendations of one WTE nursing staff to 800 live births. (The outreach service Lead Nurse should be additional to these requirements.) Explore the development of a workforce calculator to support calculations of outreach nursing workforce requirements.
2. Develop recommendations for AHP and pharmacy workforce requirements based on expert experience and advice and examples of good practice where they are available.
3. Audit the baseline recommendations as advised for psychological professionals working as part of outreach and follow-up, given the clear need for psychological support for families at this stage. Psychological professional workforce for outreach will need to be developed in conjunction with inpatient services.
4. Develop recommendations for medical workforce requirements.

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Data and Outcome Measures

Data Monitoring

- Data monitoring is an important aspect of ensuring the effectiveness and quality of neonatal outreach care services. Data collection provides valuable insights into service needs and outcomes for babies in the community.
- It is an expectation that outreach services will collect data to benchmark against standards laid down in this BAPM Framework.
- It is essential to collect local/regional data to monitor the needs and outcomes of babies and families effectively. This data collection facilitates the regional and Trust level review of trends and identification of areas where existing processes and services can be improved.
- Local/regional audit may be triggered from data review to enhance deeper understanding and quality improvement.
- A standard national approach towards evaluating neonatal outreach care should be established, including the development of a national database with agreed-upon standard indicators and metrics to ensure consistent benchmarking.
- The data collected must be of high quality and should encompass key aspects such as outreach activity, workforce, patient and family outcomes, and family experience (Table 4). This will require dedicated administrative support for data collection and reporting (see workforce section).

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Table 4: Recommendations for neonatal outreach data collection

	National	Local/Regional
Patient Data		
Gestation at birth, transfer to home and discharge from outreach		●
Growth at transfer to home and discharge from outreach		●
Feeding method and feeding intention at transfer to home		●
Referral Patterns		
Reason for referral to outreach	●	●
Where are referrals from (e.g. postnatal ward, home, local NNU/TC, other NNUs)		●
Geographic distribution		
Travel time and/or travel distance		●
Outreach Activity (e.g. monthly rates)		
Number of new referrals	●	●
Caseload - number of babies	●	●
Number of contacts and level of support	○	●
Type of contact (Face to face in home, outreach clinic, phone call, virtual live, messaging service etc)	●	●
Staffing and Resources (all disciplines)		
Commissioned WTE outreach workforce	●	●
Skill mix of outreach workforce	●	●
Training needs analysis (TNA) of outreach staff	○	●
AHP/Psychology/Pharmacy input		
Number of direct patient contacts and reason for referral	●	●
Number of indirect patient contacts and reason for concern (outreach seeking advice etc)	●	●
Attendance of AHPs/Psychology team at MDT outreach ward round	●	●
Outcomes		
Numbers of readmissions/unexpected admissions and reasons	●	●
Incident recording/error reporting	●	●
Intended feeding outcomes achieved or not	●	●
Other goals or outcomes achieved depending on service type provided (e.g. NGT feeding data, home phototherapy data)	○	●
Discharge from outreach, transfer care to health visitors or children's community nurses	○	●
Family Experience		
Family experience/feedback	●	●
Parental/care-giver confidence*	○	●
Parent-infant relationship*	○	●
Parental mental health*	○	●

● Minimum required data ○ Desirable data

*Seek advice on assessment tool from unit/Lead Psychologist &/or Occupational Therapist

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Recommendations

- There is a continuing need to monitor the impact of neonatal outreach as hospital-at-home practices are introduced, including all readmissions or adverse events.
- Routine collection of user feedback from a wide representation of service users, is important to ensure that family needs are being met.
- The development and implementation of a standardised national survey to gather consistent data on family experience is recommended. Local/regional teams may adapt or expand upon this survey to effectively monitor their specific practices.
- Further research is needed to identify the most appropriate screening tools for assessing parental mental health, the parent-infant relationship, and parental confidence. Suggested resources are listed in Appendix K.

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NNOG Parent Survey

Supporting families at home

WHAT DID WE ASK?

Questions to determine how well families are supported at home

WHO ANSWERED?

396

Neonatal Parents & Carers in 6 weeks

ARE YOU WELL SUPPORTED?

YES - 65%

NO - 35%

The babies

Length of stay 0-200 days
Majority spent time in neonatal unit < 3 years ago

All gestations
Majority born before 34 weeks

All discharge weights
Majority over 2kg

Majority had no ongoing medical issues on leaving hospital

87 had home oxygen

83 had a nasogastric tube

Outreach

56%

of families had support from neonatal outreach services

81%

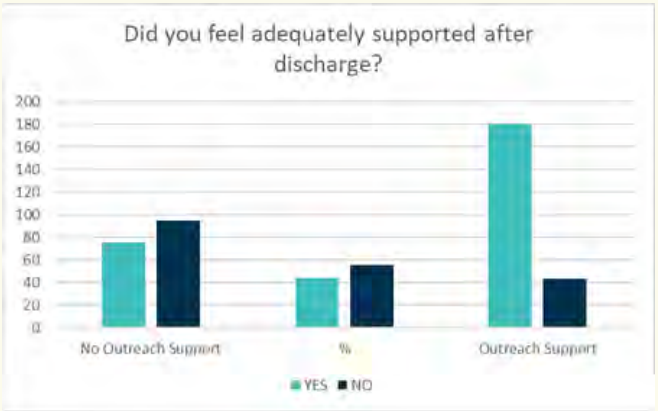
of families being supported from neonatal outreach felt well supported

66%

of families being supported from their health visitor felt well supported

"The outreach team soon became like family"

"Knowing we had the NCOT service made all the difference"



"I would have benefitted from an outreach team for support as I only had my health visitor and other NICU mums. Going to hospital for help sometimes felt overkill"

Care aspects most important to families

1st Health Checks
I.e. Blood Tests, Oxygen Monitoring, and general health review

2nd Growth Monitoring

3rd Feeding Support

4th Mental Health & Wellbeing

5th Liaision with hospital team

6th GP Support

7th Signposting for follow up appointments

NNOG Parent Survey

Supporting families at home

"The neonatal outreach team were brilliant - attentive, personal, informative. They gave me reassurance and confidence that my son was ok"

"My GP was fab noticing postnatal anxiety but I felt I could've done with specific neonatal care rather than just a health visitor. My health visitor wasn't always aware of premature baby concerns"

"Medical professionals were there for medical aspects but not my wellbeing"

"Health visitor reassurance was a god send"

"The dietician team continued to support me and check on my daughters growth"

"The Speech and Language Therapist was incredible. So helpful and supportive. The Occupational Therapist also really helped me to know what to focus on so my child caught up on gross and fine motor skills"

What areas would families like more support with post discharge?

1. MENTAL HEALTH
2. FEEDING SUPPORT
3. INCREASED HEALTH VISITOR SUPPORT
4. REFLUX MANAGEMENT
5. DEVELOPMENT & MILESTONES
6. TELEPHONE CALL POST DISCHARGE

Despite not asking directly....

94 Parents highlighted a need for further mental health support

8 Mentioned their experiences of PTSD or Trauma

"Neonatal community nurse was amazing support but mental health support nonexistent"

"Mental health support should also be issued/offered as routine, I struggled with birth trauma and PTSD and it took so long to get the help and support I needed"

50 Parents highlighted a need for further feeding support

20 Parents highlighted a need for additional breastfeeding support

"I asked several times to see the breastfeeding specialist as I was struggling so much with expressing/trying to feed and it took nearly a week for her to come by which time i'd given up as I was in so much pain and baby was now settled on bottle feeds."

A need for hospital at home

"My baby was tube fed in hospital, then we were encouraged to bottle feed so we could go home quicker"

A National Survey on Neonatal Community Outreach Services

Chuen Wai Lee[1], Rebecca Smith[2], Claire Salgin[3], Burak Salgin[1]

Authors affiliation: 1. Neonatal Intensive Care Unit, The Royal London Hospital, Barts Health NHS Trust, 2. Neonatal Outreach Services, Neonatal Intensive Care Unit, The Royal London Hospital, Barts Health NHS Trust, 3. Neonatal Community Outreach Services, Chelsea and Westminster Hospital NHS Foundation Trust

BACKGROUND AND AIMS

- The aim of neonatal outreach services is to provide specialist neonatal care to babies at home.
- This facilitates early discharge, and family-centred care by empowering parents and supporting families at home.
- A national framework for neonatal discharge planning and follow up was published in Scotland in 2019, however there are currently no national frameworks for neonatal outreach services in England and Wales.

METHODOLOGY

- A national survey was conducted to benchmark current practice across all neonatal units with dedicated neonatal outreach services across England, Wales and Scotland.
- The survey covered four main areas (1) resources available to dedicated neonatal outreach teams; (2) outreach service spectrum such as information on home visits, patient load and discharge planning; (3) service provision; and (4) support available for outreach teams.
- 177 neonatal units in England, Wales and Scotland were contacted by phone to identify dedicated neonatal outreach teams (NCOTs).
- This project was registered with the Clinical Effectiveness Unit at Barts Health NHS Trust.

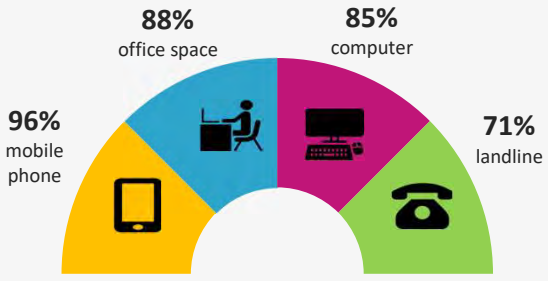
RESULTS

- 111 NCOTs were identified covering 129 out of 179 (72%) neonatal units across England, Wales and Scotland.
- The survey was sent to all NCOTs by email with an 85% response rate between May 2022 – Dec 2022.
- 95% of all NICUs (52/55), 65% of LNUs (53/81), and 54% of SCBUs (24/43) have dedicated NCOT services.

Neonatal Outreach Service Resources

NCOTs are located within the neonatal unit
The remaining are either on PNW/TC, in the CCNT office or somewhere else in the hospital.

NCOT services cover a defined catchment area
However, 44% of NCOTs have cared for babies outside of their catchment.

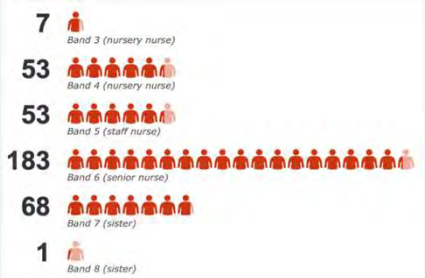


Dedicated resources for NCOTs
The values above indicate the percentage of NCOTs with the dedicated resource available to them

Total number of dedicated nursing staff across all NCOTs nationally

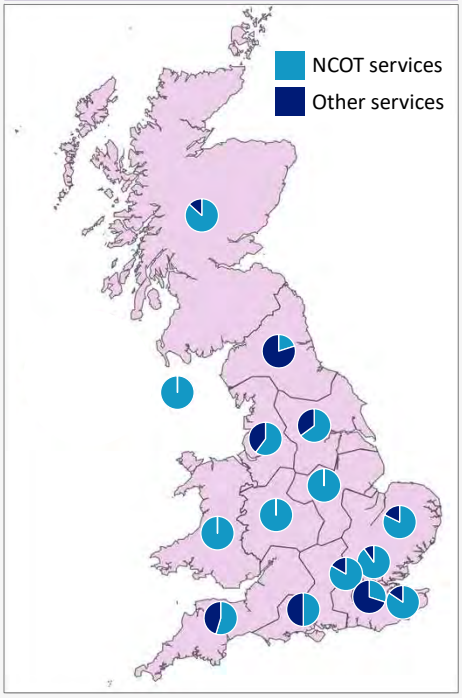
5 NCOTs are made up of only 1 nurse: 3 of these have a Band 6 or 7 nurse and 2 have a Band 7 nurse, a named consultant and admin staff.

Other dedicated staff include a named consultant **31%** and administrator **23%**



The number of neonatal units with dedicated NCOT teams within ODNs in England, Wales and Scotland.

Operational Delivery Network	No. of neonatal units	Units with dedicated NCOT
West Midlands Neonatal	14	14(100%)
East Midlands Neonatal	11	11(100%)
Wales	9	9(100%)
Isle of Man	1	1(100%)
North Central & North East London Neonatal	10	9(90%)
Scotland	15	13(87%)
South East Coast Neonatal	13	11(85%)
North West London Neonatal	6	5(83%)
East of England Neonatal	17	14(82%)
Yorkshire & Humber Neonatal	17	11(65%)
North West Neonatal	20	12(60%)
South West Neonatal	12	7(58%)
Thames Valley & Wessex	14	7(50%)
South London Neonatal	10	3(30%)
Northern Neonatal	10	2(20%)
TOTAL	**177**	**129(72%)**



WeCare

NHS Barts Health NHS Trust

Neonatal Outreach Service Spectrum

50% NCOTs care for up to 20 babies at any point in time
15% care for up to 10 babies; 35% 11-20 babies

58% NCOTs follow babies for up to 2 months
27% follow babies 0-1 months; 31% 1-2 months

75% NCOTs care for home oxygen babies for up to 6 months
35% care for babies 1-2 months; 10% 3-4 months; 30% 5-6 months

82% NCOTs have an agreed pathway for babies to be eligible for their service

36% NCOTs provide a 7 day service Mon-Sun
37% provide Mon-Fri service; 23% provide additional service on Bank Holidays

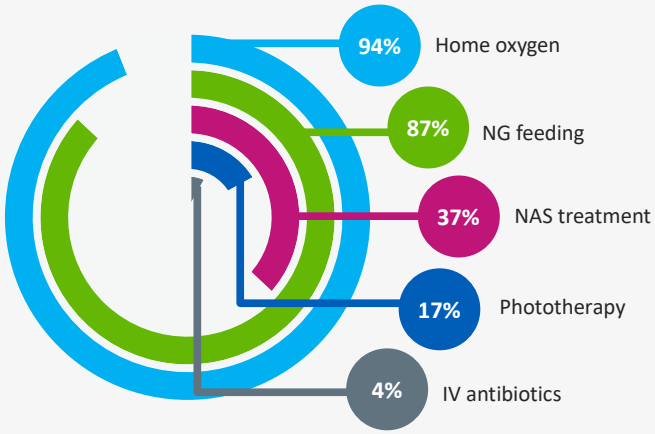
45% NCOTs have on average 5-10 home visits per week
Most home visits take up to 30 min travel time

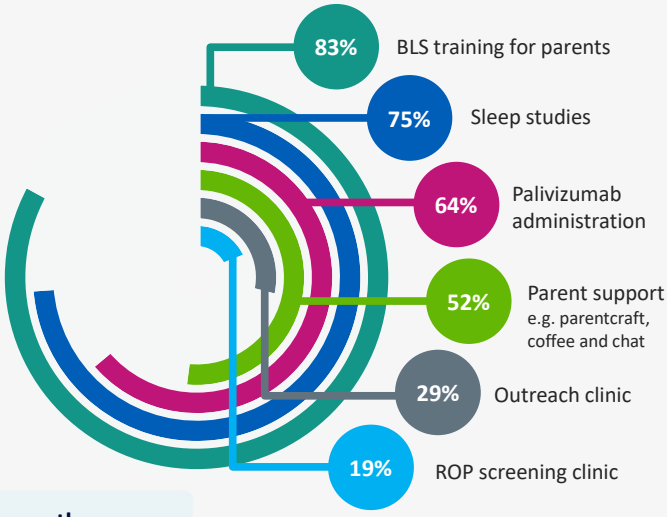
NCOT Discharge Planning

51% Are responsible for leading discharge
71% Meet families before discharge
98% Know about baby and home arrangements before discharge
98% Parents are given appropriate contact information

Neonatal Outreach Service Provision

- The range of services provided by NCOTs nationally



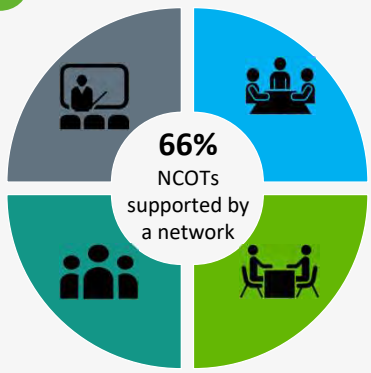


88% NCOTs have established links with both **dietician**, and **speech and language therapy**

Support for Neonatal Outreach Teams

Network Meetings
- Peer support
- Shared learning
- Guidelines and care pathways

Outreach Interest Network Groups
- Share ideas



Network Study Days
- Review service provisions across network
- Ensure equity across the network
- Review workload for teams across the network
- Discuss development or practice improvements
- Standardise care across network
- Discuss referrals from other teams within the network

Supervision Meetings

CONCLUSION

- The survey revealed a wide variation in the size and provision of NCOTs.
- While there is a framework for a model for neonatal liaison services in Scotland https://www.perinatalnetwork.scot/neonatal/neonatal-discharge/, there are currently no national frameworks in England and Wales.
- The results of this survey will help to highlight and inform outreach teams on the current practices across all neonatal units and provides a benchmark for NCOTs aiming to develop or expand on their services.

ACKNOWLEDGEMENTS

- We would like to thank all the NCOT teams for their time and feedback
- UK map adapted from https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data-analysis-unit/map-of-uk-neonatal-units/
- Icons from https://onlinewebfonts.com

Appendix C: Additional supportive literature

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Appendix D: Network/ Regional Lead Neonatal Outreach Role Profile

- Provision of professional leadership for neonatal outreach services enabling continuous strategic overview, service mapping, identifying gaps, and the development of neonatal outreach services.
- Provide oversight, quality assurance, and regional monitoring of neonatal outreach services. Support the delivery of national guidance, standards and best practice.
- Facilitate the development of shared protocols and standards, improving quality and equity of care.
- Provide expert clinical, service development and strategic advice and support for recruitment and retention of neonatal outreach teams.
- No direct patient care but working closely with all neonatal outreach teams across the region, including on-site presence at all regional units.
- Supporting innovative ways of delivering care at home to ensure families are discharged earlier, safely, well supported, and there is equitable access to neonatal outreach services across the region.
- Facilitating shared learning and developing education and training packages and competencies for neonatal outreach teams in line with evidenced based practice.
- Monitor and analyse family experience to provide local or regional feedback to improve family experience when being discharged from the neonatal unit and transitional care and improve health outcomes.
- Communicating and collaborating with commissioners, internal and external stakeholders, and providers to support a consistent regional service delivery of neonatal outreach services working seamlessly across internal specialty boundaries within maternity and neonatal units.
- Supporting development of local business cases for neonatal outreach.

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Appendix E: Neonatal outreach clinic example

The Royal Cornwall Trust Neonatal Outreach Service covers 1375 square miles which is most of the county of Cornwall. Cornwall has very few areas of dense population but a lot of smaller towns and villages.

The outreach team wanted to look at how they could work smarter in managing their caseload as well as reduce isolation for families and facilitate peer to peer support. A mid county location of Perranporth was selected as the venue for neonatal outreach clinics to run.

The clinics are delivered in a free family hub via local council. Risk assessments and public liability considerations were all taken into account. Charity funds are used to cover sundries/ initial set up equipment. The clinic started fortnightly but now runs weekly with a new venue being added elsewhere in the county to enable more families to attend. Initially these were 2 hour clinics but have recently expanded to 4 hours.

The clinic provides a safe environment for families of NNU/TC infants and attendance is invite only. The clinic is now jointly run by the outreach nurses, neonatal infant feeding team, dietitians and clinical psychologist. This maximises opportunities to facilitate MDT face to face follow up. The physio and OT are also keen to become involved.

There are two rooms; one is used for all the clinical contact eg observations and growth monitoring while the other larger room provides families the space and time to enjoy less intrusive activities eg infant massage and support, along with tea, coffee and cake. The aim is to provide a neurodevelopmentally appropriate environment for ex NNU infants.

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Appendix F: Examples of good practice from neonatal outreach teams

Outreach Service in Medway hospital (Kent, Surrey and Sussex ODN)

The process of building relationships and preparing families for home:

- The outreach team review BadgerNet each morning 7 days a week and check for any new admissions. If the babies / families are assigned an Outreach Nurse.
- Introductions are made with the family as soon as it is appropriate, then regular check-ins with the family for the duration of their baby's stage, which includes signposting and referrals (counselling, financial support, health and well-being, charity referrals for further support, etc). Prior to discharge the team will 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.).
- Our office is based on the ward, so an open door policy for families to come and seek us if they feel they need extra support. We are visible on the unit, attend ward round daily 7 days a week, including parent led ward rounds with the wider MDT/AHP team. We phone families for contact whilst babies are inpatients to check-in on parents if they are not able to attend the unit.
- The family receive a phone call the morning following discharge and the first home visit is then booked, with visiting continuing until the baby is feeding and growing well, and the families have the right support in place like mental health and wellbeing.
- We do not like to stop contact if there is a gap between the next service taking over.

Outreach Service in South Tees Hospital (Northern Network)

- Telephone call to every family who have gone home from the Neonatal unit, regardless of postcode. During this phone call we make sure the family/carer has a copy of the discharge letter and they understand what is written in it. We make sure that they know who is looking after/supporting them.
- Inform the HV of discharge from the unit and connect them with the family if they haven't already done so.
- Held a Focus month on unit- 'Life beyond the Neonatal unit', why we do what we do and the impact this has on the future of the family. Lots of short sessions from external services and allied health professionals i.e. speech and Language, OT, dietitian, physiotherapy, hearing screening, local hospice, National literacy hub, family hubs, clinical psychologist, Outreach etc.
- We have been working closely with the Family Hubs, Best Start to Life programme that focuses on the importance of the first 1,001 days and how this time shapes the future of the child's life. We have worked with two of our local authorities to provide a peer support group utilizing the government initiative. The group is facilitated by the family hubs as a peer support group but also accessed and supported by the wider MDT and other commissioned services. The programme discusses the importance of having a single point of access, allowing for the families to have the right information at the right time. The group supports families on their journey and hopefully helps to build a better future by bridging the gap between inpatient and community care.
- We have recently evaluated the Neonatal support group with the support of the psychology team. The data was collected through a questionnaire and was a mixture of quantitative and qualitative data reflecting on people's experiences. The results were statistically significant and the overall mean scores show an improvement in family wellbeing after attending the group (mean pre group 6.46, mean post group 8.62). There were two common themes that emerged:
    1) Connectedness to others-people valued being able to meet with others who had been through similar experiences to themselves.
    2) A supportive environment, parents attending the group found it really beneficial having professionals attending the group as they could ask questions and seek advice.

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Neonatal Outreach Service: North West Anglia NHS Foundation Trust
Covering Peterborough City Hospital and Hinchingbrooke Hospital (East of England ODN)

• Adaptations during COVID-19

During the COVID-19 pandemic, we established a remote working team and transitioned all processes to electronic systems, including patient notes. This allowed us to continue visiting families while minimizing hospital footfall. The lead nurse for outreach was based in the hospital, coordinating discharges and meeting parents, a practice that has continued post-COVID. The lead nurse now also attends ward rounds twice weekly, alongside psychosocial meetings.

• Hybrid Roles

We introduced hybrid roles to strengthen the connection between outreach services and neonatal units. This approach helps build relationships with families before discharge home. For example, we now have a joint hybrid role focused on outreach and infant feeding, which supports families dealing with more complex feeding challenges. Another hybrid role involves a nursery nurse supporting both outreach and the ward, assisting with discharge planning.

• Pre-Discharge Visits

We implemented pre-discharge home visits for babies transitioning from NICU/SCBU to better prepare families. These visits include teaching parents' basic life support (BLS). Parents feel they can concentrate and retain information better in their own environment. The visits also cover parent craft training to complement ward-based education, helping parents to feel more confident.

• Family Visits

We visit all babies who have spent five or more days in NICU or any term baby under 37 weeks or 2.5 kg, including babies on the transitional care units. Every family receives regular visits from our team.

• Additional Support and Training

Two team members are now trained in Newborn Behavioural Observations (NBO) and can provide additional visits. We also offer baby massage classes—one group per hospital site. Before starting, parents are added to a WhatsApp group (with their permission) for ongoing updates and outreach messages. Once the classes are completed, parents continue to stay connected through the group, fostering long-term peer support. For families facing challenges, we also offer baby massage sessions at home.

• Peer Support Groups

We manage several WhatsApp peer support groups, tailored to specific needs:

• A general group for all babies who have been in NICU
• A group for parents of multiples
• A home oxygen support group
• A group for families of babies with Trisomy 21

Outreach Service in Gorleston-on sea (East of England ODN)

- Each family has a named outreach nurse who parents can go to but also parents have knowledge of who works in the team so that they know there is a team working together to support them
- MDT working. When we have a complex infant an MDT thread email is set up which includes every professional involved with that infant and family so that communication is efficient. This ensures that everyone is working to the same goals and is up to date with any changes.

Outreach Service in Southampton (Thames Valley and Wessex ODN)

- Southampton Neonatal Outreach Service launched in 2013. The team offers daily support across the neonatal unit, transitional care (postnatal ward), and in the community.
- The team meet the families on the neonatal unit and assist in the management and care of babies on the transitional care unit (on the postnatal ward). The nursing team is made up of nursing bands 4-7 and they are supported by psychology, medical, surgical, allied health professional colleagues, and a feeding support team.
- Support is offered to families who have babies on home oxygen, short-term naso-gastric tube

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feeding, feeding and weight reviews, blood sampling, and support the transition from hospital to home. They provide home visits, telephone calls, and in-reach support.

- Recently the team have commenced a home phototherapy service to promote earlier discharge and reduce readmissions for jaundice.

Hospital at home

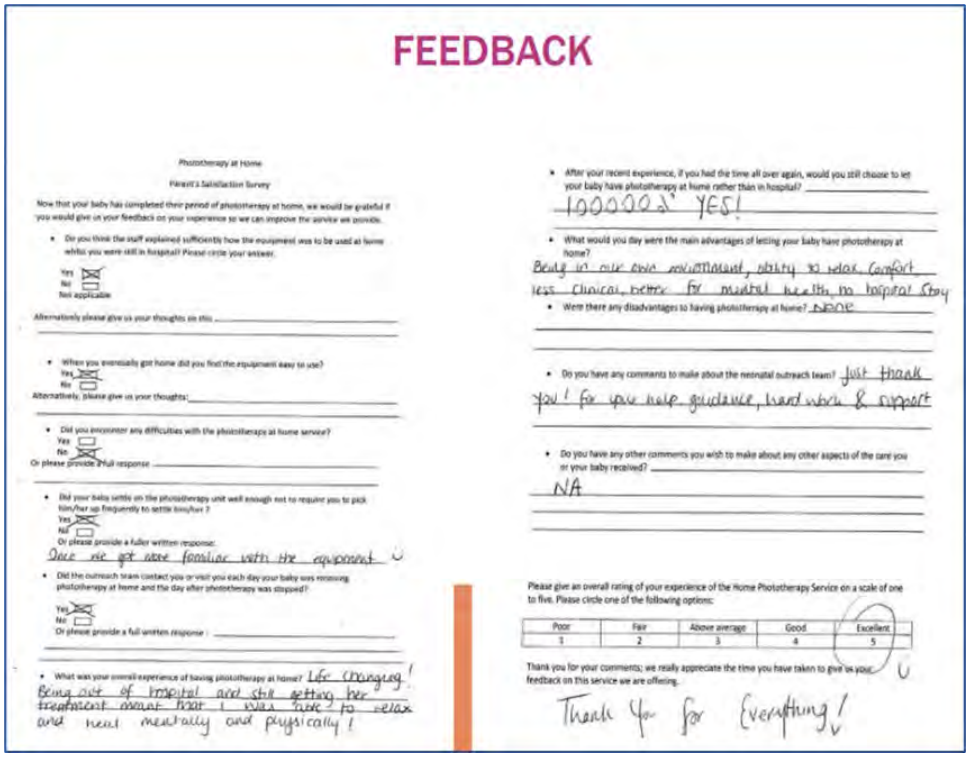
Home Phototherapy Programme in Birmingham

- Trialled home phototherapy in 2018. Introduced programme in 2019.
- Now have an established service taking on both hospital and community-initiated patients.

Babies eligible for home phototherapy:

- Gestational age >35 weeks, Age >48hrs, Birth weight >2kg.
- Clinically stable.
- Serum Bilirubin <50mmol/l above phototherapy threshold (NICE guidelines).
- No risk factors for jaundice, and no elevated conjugated hyperbilirubinemia.
- No safeguarding concerns.
- Normal basic diagnostic workup (History, examination, baby blood group, maternal blood group, DAT, and G6PD, where applicable).

This has received positive feedback from families and the team have shared their practices with other networks.



FEEDBACK

Phototherapy at Home

Parent's Satisfaction Survey

Now that your baby has completed their period of phototherapy at home, we would be grateful if you would give us your feedback on your experience so we can improve the service we provide.

- Do you think the staff explained sufficiently how the equipment was to be used at home while you were still in hospital? Please circle your answer.

Yes ☒
No ☐
Not applicable

Alternatively, please give us your thoughts on this: _____

- When you eventually got home did you find the equipment easy to use?

Yes ☒
No ☐

Alternatively, please give us your thoughts: _____

- Did you encounter any difficulties with the phototherapy at home service?

Yes ☐
No ☒

Or please provide a full response: _____

- Did your baby settle on the phototherapy unit well enough not to require you to pick him/her up frequently to settle him/her ?

Yes ☒
No ☐

Or please provide a fuller written response:
Once we got more familiar with the equipment

- Did the outreach team contact you or visit you each day your baby was receiving phototherapy at home and the day after phototherapy was stopped?

Yes ☒
No ☐

Or please provide a full written response : _____

- What was your overall experience of having phototherapy at home? Life changing! Being out of hospital and still getting her treatment meant that I was able to relax and heal mentally and physically!

- After your recent experience, if you had the time all over again, would you still choose to let your baby have phototherapy at home rather than in hospital? _____
100000% YES!

- What would you say were the main advantages of letting your baby have phototherapy at home?
Being in our own environment, ability to relax. Comfort less clinical, better for mental health, no hospital stay

- Were there any disadvantages to having phototherapy at home? NONE

- Do you have any comments to make about the neonatal outreach team? Just thank you! For your help, guidance, hard work & support

- Do you have any other comments you wish to make about any other aspects of the care you or your baby received? _____
NA

Please give an overall rating of your experience of the Home Phototherapy Service on a scale of one to five. Please circle one of the following options:

Poor	Fair	Above average	Good	Excellent
1	2	3	4	5

Thank you for your comments; we really appreciate the time you have taken to give us your feedback on this service we are offering.

Thank You for Everything!

Peer support groups

East of England ODN
The Neonatal Community Team hold a 'Drop in and Chat' groups.

They hold two groups each month across the LMNS. A member of the team is available to have a chat with families in an informal environment. The team can assess babies offering growth monitoring if required.

Rotherham (Yorkshire & Humber ODN)

- Rotherham neonatal outreach team run a peer support group once a month at a local play centre. They use the 'party' room which is separate to the main play area. They alternate having just peer support with toys one month and then the alternate month they have a Baby Sensory session.
- Regular expert speakers at a neonatal outreach team drop-in session to support staff education – Held by Care Coordinators across the ODN.

Countess of Chester Hospital (North West ODN)

- Chester run a peer support group called 'Dinky Deva's . The group established in 2017 and ran several different groups/meet ups and a lively Facebook group. Currently we offer a Wednesday morning 'babes in arms' coffee morning for anyone who has been on NNU and it is held on the unit and well attended every week along with families that are on the unit. Booking is encouraged and facilitated by one of our peer supporters via the Facebook group. It is supported by the local Perinatal mental health nurse and a Perinatal Parent Infant Practitioner facilitates things like baby massage, sensory play ect, our AHP's also regularly attend.
- As an outreach team we run a clinic with our lactation consultant and infant feed lead
- We also offer a family social every second Sunday of the month, where families are invited to attend a walk around the country park which is not far from the unit and then they can come back to the garden for tea and cakes (we are lucky enough to have a garden and log cabin to facilitate this) . Rain or shine these go ahead so families know it's a consistent offering and is facilitated and supported by a group of volunteers who have had a baby on the unit.
- Working collaboratively with AHP's and Wellbeing practitioners has proven invaluable for families when transitioning to home. The wellbeing practitioners continue to follow up phone calls after discharge and we as a team can make referrals post discharge (we are finding most families engage more with Wellbeing post discharge).

Liaising with AHPs

Stoke Mandeville Hospital (Thames Valley & Wessex ODN)

- Stoke Mandeville neonatal outreach nurses liaise closely with the AHP team. They often email AHP's if there are any concerns with patients' appointments. In the North of the county the neonatal outreach nurse regularly attends multidisciplinary appointments with SALT, physiotherapist, and the occupational therapist. This is beneficial as all health professionals are up to date with agreed future care plans. The team also attend feeding clinic appointments with the SALT and dietitian, and developmental care ward rounds on the neonatal unit once a fortnight (attended by physio/OT/SALT/dietitian), allowing for joined up MDT working.
- The most important benefits being limiting appointments as some families have many

appointments and this can take up lots of their time. It also reduces trauma as they don't have to rediscuss the birth history to each individual as it is all done in one appointment (which has been mentioned by one of the families recently).

- We hope to set up a 'one stop shop' with everyone involved in the babies care in one room and exploring how this can be done and standardise it across the county.

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Appendix G: Responsive feeding for the transition to home

That where babies can, they should be fed responsively at regular intervals by their preferred method of oral feeding for 48 hours prior to discharge from the neonatal unit. They should be demonstrating effective oral feeding consistently to maintain nutritional intake to support growth. If a baby is not consistently waking or showing feeding cues, those feeds should be given via the baby's NG tube. Babies can be discharged home with an NG tube in place to support their ongoing feeding journey and the transition from tube to oral feeding.

Effective oral feeding means a baby can:

- Wake, show feeding cues and maintain a quiet alert state.
- Maintain a stable heart rate, respiratory rate and oxygen saturations.
- Maintain position, latch and attachment for oral feeds.
- Coordinate sucking, swallowing and breathing together during oral feeds.
- Maintain a calm, quiet and alert state throughout oral feeds.

For those babies who are establishing oral feeding following a cue-based approach, and where they continue to require tube feeds to meet their nutritional requirements, ongoing AHP assessment and support including SLT may be necessary.

Babies are often discharged from the neonatal unit while they are still developing their feeding skills or while they are still working on establishing their feeding skills. Whilst some babies may be able to feed, skilled feeding, co-ordination and organisation does not occur until post-term.

Cue based care begins on the neonatal unit and does not stop at the point of transition home. Recognising and responding to their baby’s feeding cues is an essential skill for parents in learning how to support their baby’s feeding development and ongoing progress with eating and drinking in the early years.

It is important for neonatal MDTs, including neonatal outreach teams, to collaborate closely with the AHP team within the unit, where available. In cases where neonatal SLT provision is not accessible, referrals to community paediatric AHP teams including SLT can be made for ongoing support.

Tools such as the UNICEF Breastfeeding Assessment Tool can be used with parents and caregivers to guide a baby’s feeding development on a neonatal unit and for their ongoing care and transition to home.

Breastfeeding assessment tool - neonatal (unicef.org.uk)

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Appendix H: Service model examples from across UK

Individual trust service model example

The University Hospitals Plymouth NHS Trust Neonatal Outreach Service (NOS) has been a commissioned service since 2011. Initially operating 5 days/week, it was increased to 7 days/week service in 2014 following an audit into cot blocking at weekends. There are 2 staff on each day, 1 x 0800-16.00 & 1 x 08.00-18.00.

The service workforce consists of:

- Senior Sister for Transitional Care & Outreach 0.8-1wte
- NOS nursing team - 3.7WTE
- TC/PN Consultant on Service for advice and direction
- Collaboration with AHPs to ensure comprehensive discharge planning

UHPT has an 18 cot Transitional Care Ward which is where the NOS is based. Admission to TCW follows the BAPM framework which enables step down from the NNU to TC. Most infants discharged home from TC rather than NICU. The NOS staff work closely with the TC staff to support discharge planning and preparation.

The NOS supports safe transition from hospital to home including:

- Home oxygen.
- Short term enteral tube feeding whilst establishing full oral feeds at home. This facilitates earlier discharge, reuniting the family at home sooner and enhancing cot capacity on the neonatal unit and transitional care.
- Neonatal Abstinence syndrome treatment and support.
- Palliative care, end of life care and bereavement support. Members of the team have completed the Enhancing Practice in Paediatric Palliative Care module and bereavement support training with Cruse UK. Bereavement support is offered as a bespoke service to meet the parents' individual needs.
- Home phototherapy. In 2023 home phototherapy was introduced. First 6 months of service delivery supported 25 families to receive home therapy. The NOS also completes SBR monitoring in the home for infants who are borderline for treatment, thus reducing the foot fall in hospital and preventing disruption to families with a new baby.

LMNS Hub & Spoke model example

This service is between three trusts (University Hospital Coventry and Warwickshire (UHCW), South Warwickshire Foundation Trust (SWFT) and George Eliot Hospital (GEH)) but all within the same LMNS. Coventry as the NICU is the hub and host trust for finance and contracts, the other two units are SCUs.

The service was launched in September 2021 following project development with support and close working from the neonatal/paediatric matrons from each of the 3 trusts. The service was launched as a 6 day/week with on-call on Sundays initially but with the launch of home phototherapy now operates 7 days/week, 365 days a year with at least 4 staff on each week-day and 3 on each weekend day or bank holiday.

The service workforce consists of:

- 1.0wte band 7 lead
- 6.29 wte Band 6 Neonatal Outreach Nurses

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- 1.0wte Band 4 Senior Nursery Nurse for outreach services
- 0.8wte Band 4 Neonatal Outreach Senior Administrator
- 0.52wte Band 3 Neonatal Outreach Administrator
- The outreach services team is supported by a neonatal consultant based at UHCW who has taken on the additional role of Lead Consultant for outreach services. In the lead consultant for outreach services' absence, the team would escalate any concerns regarding baby's progress at home to the service week consultant at the trust that baby was discharged home from.

Neonatal AHPs are in post and work across the LMNS in a hub and spoke model similar to outreach services. Unfortunately, there is currently no funding for the neonatal AHPs or community AHPs to provide support at home for outreach service patients. Advice is sought on a goodwill basis from the AHPs both at the hospital and in the community.

The team have an office based at UHCW. There is a Duty Outreach Nurse on each day based at UHCW to coordinate the team and be available for any queries. One nurse is then allocated for GEH, and another nurse for SWFT. These nurses will visit the sites to obtain an update regarding the babies and speak with parents. Another nurse will be allocated Home Phototherapy. It is their responsibility to review and action blood results each shift. Outreach services have a Team huddle each morning to help plan for the day. They have an additional huddle on a Friday afternoon to plan for the weekend.

All relevant guidelines/pathways are agreed between all 3 trusts and carry the logos of all 3 as well as the LMNS logo. All outreach staff have access to Badgernet at all 3 sites, as well as maternity Badgernet for home phototherapy.

The NOS supports safe transition from hospital to home including:

- Home oxygen.
- Short term enteral tube feeding whilst establishing full oral feeds at home. This facilitates earlier discharge, reuniting the family at home sooner and enhancing cot capacity on the neonatal units.
- Home phototherapy.
- Weight monitoring – for babies discharged weighing less than 1.8kg.

Network Hub & Spoke Model Example

The East Midlands Neonatal Network Homecare service supports all 11 trusts within the network. The homecare service was set up to promote equity of support and service to all families. Units in the network to all offer the same service. The service is divided into 2 hubs; the North Hub and South Hub.

There are 4 trusts (Leicester General, Leicester Royal, Kettering and Northampton) within the South Hub with Leicester General acting as the host trust and hub for the model with the other 3 sites being the spokes. The service operates 7 days/week with 5-8 staff on 8-5 each weekday and 3-4 on weekend days.

The service workforce consists of:

- 1.0wte band 8a lead
- nursing team -1.69 wte bd 7, 8wte bd 6, 0.4wte bd 5 & 4.2wte bd 4
- administrator – 1.0 wte
- Neonatal Consultant lead for homecare in Leicester and a link consultant in the other sites
- Link with AHPs in each NNU

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- Duty band 6 on each day at Leicester and a team huddle each morning to help plan for the day. The duty band 6 is also available to meet with families prior to discharge in Leicester. This is done by other team members in the other sites.

All relevant guidelines/pathways are agreed between all trusts. All outreach staff have access to Badgernet at all sites with an information sharing contract.

The team supports safe transition from hospital to home including:

- Home oxygen
- Short-term enteral tube feeding whilst establishing full oral feeds at home. This facilitates earlier discharge, reuniting the family at home sooner and enhancing cot capacity on the neonatal units.
- Home phototherapy commenced in Leicester 18 months ago and was then cascaded out to the other sites and 369 babies so far have received home phototherapy.
- Infants with complex health care needs, including surgical follow up, infants with HIE grade 3 or 4
- All babies born <34 or <1.8kg

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Appendix I: Examples of Network-wide and national shared learning opportunities

Programme of virtual Outreach study day held by West Midlands Perinatal Lead AHP & Psychology team (left) and Home Oxygen Webinar organised by the South East Neonatal Outreach Project Lead (right).

Networks Neonatal Outreach Group (NNOG)

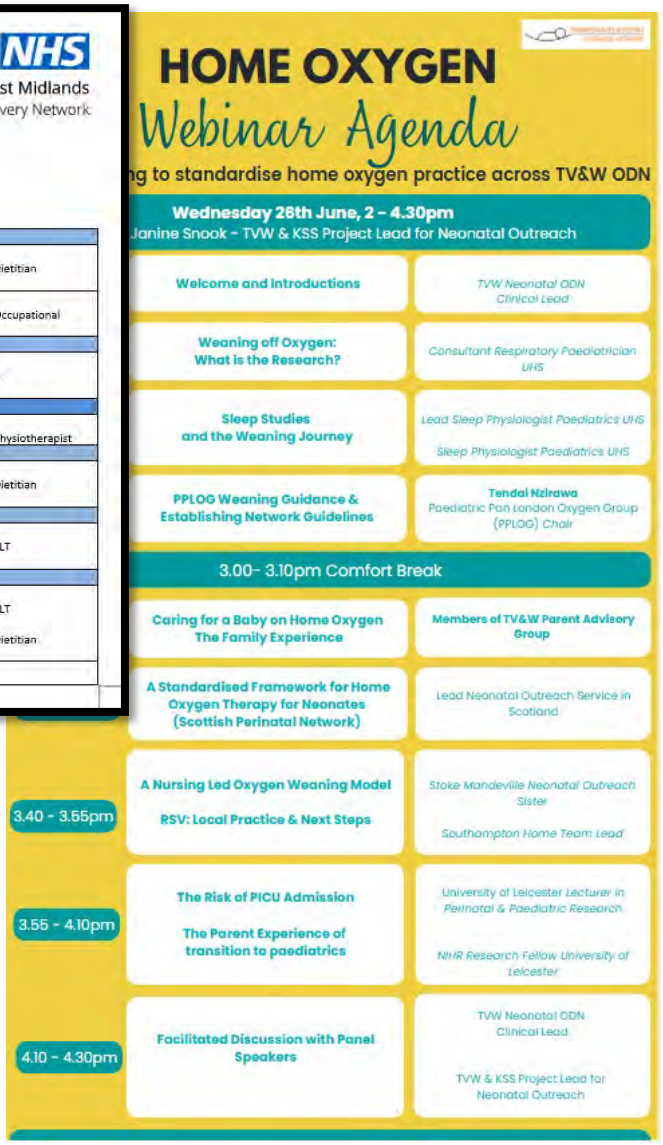
The Purpose of the group is to provide a structured approach to sharing and comparing practice and evidence, to identify best practice and improve the parent and family experience, discuss challenges, and assist in developing national standards. The NNOG will facilitate effective communications between networks and other stakeholders.

NHS
West Midlands
Neonatal Operational Delivery Network

NCOT Therapies at Home

Date: Thursday 19th May 2022
Venue: online

8.45-9.00	REGISTRATION OPENS	
09:00-09:15	Welcome & Introduction	Lead Neonatal Network Dietitian
09:15 – 10.15	Transitioning home – supporting babies needs	Lead Neonatal Network Occupational Therapist
10: 15- 10.30	COFFEE	
10:30– 11.30	A trauma-informed approach to supporting families post-discharge	Lead Clinical Psychologist
11.30-11.40	Comfort break	
11.40-12.30	Supporting Physical Development at Home	Lead Neonatal Network Physiotherapist
12.30-13.30	LUNCH	
13:30- 14:30	Assessing Growth- how much is enough?	Lead Neonatal Network Dietitian
14:30– 14:40	Comfort break	
14:40 – 15:15	Responsive Feeding	Lead Neonatal Network SLT
15:15 -15:30	TEA	
15:30 - 16:30	Launch of Feeding and Nutrition Screening Tool	Lead Neonatal Network SLT Lead Neonatal Network Dietitian
16:30 -16:45	Questions and Close	



HOME OXYGEN
Webinar Agenda
g to standardise home oxygen practice across TV&W ODN

Wednesday 26th June, 2 – 4.30pm
Janine Snook – TVW & KSS Project Lead for Neonatal Outreach

Welcome and Introductions	TVW Neonatal ODN Clinical Lead
Weaning off Oxygen: What is the Research?	Consultant Respiratory Paediatrician UHS
Sleep Studies and the Weaning Journey	Lead Sleep Physiologist Paediatrics UHS Sleep Physiologist Paediatrics UHS
PPLOG Weaning Guidance & Establishing Network Guidelines	Tendai Nzirawa Paediatric Pan London Oxygen Group (PPLOG) Chair
3.00- 3.10pm Comfort Break	
Caring for a Baby on Home Oxygen The Family Experience	Members of TV&W Parent Advisory Group
A Standardised Framework for Home Oxygen Therapy for Neonates (Scottish Perinatal Network)	Lead Neonatal Outreach Service in Scotland
3.40 - 3.55pm A Nursing Led Oxygen Weaning Model RSV: Local Practice & Next Steps	Stoke Mandeville Neonatal Outreach Sister Southampton Home Team Lead
3.55 - 4.10pm The Risk of PICU Admission The Parent Experience of transition to paediatrics	University of Leicester Lecturer in Perinatal & Paediatric Research NIHR Research Fellow University of Leicester
4.10 - 4.30pm Facilitated Discussion with Panel Speakers	TVW Neonatal ODN Clinical Lead TVW & KSS Project Lead for Neonatal Outreach

Appendix J: Allied Health Professionals, Psychology examples of working with Neonatal Outreach Services

Collaborative working with Allied Health Professionals

A strong collaborative working relationship between Neonatal Community Outreach Team (NCOT) teams and AHPs is a valuable support for the NCOT team, the baby, and their family.

During the introduction of AHPs to neonatal services, which includes transitional care and NCOT there was a lot of collaboration to understand each other's roles to establish how we could best support the babies and their families in our care. Observing NCOT visits or AHPs interventions with babies and their family was a valuable way of understanding each other role and how best we could optimise our collaborative working.

AHP's input for the outreach services team is beneficial to maximise baby's long-term outcomes.

"Our NCOT team has benefitted greatly from the introduction of AHP's to neonatal services. As the NCOT team is deemed as hospital at home and under the umbrella of neonatal services, babies under our care and their family have been able to access and continue the valued support of the AHPs. We feel we are optimising the care and potential to these babies short and long term outcomes and look after both theirs and their family's wellbeing." Vicky, NCOT, Worcester

Occupational Therapist

Providing support for a baby's development during their stay will optimise their development potential. Prior to discharge a plan with the occupational therapist and the multi-disciplinary team can be developed to support the baby and family at home to optimise the baby's developmental outcomes. During this time collaborative contacts with the family can highlight the importance of this.

"Following discharge to the outreach service, collaborative working between the team and the OT will provide the family with optimal developmental support for their baby. Support can be provided to outreach with advice and guidance or direct with the family where appropriate by telephone contact or when deemed necessary a dual visit accompanying the outreach service to visit the baby and family.

"The integration of AHP services into the acute neonatal unit has offered the opportunity for therapists and Outreach nurses to be able to link together for smoother and timelier access to support and advise for our pre-term infants who have been discharged under Outreach services care. This holds potential for Occupational Therapy to continue to support with early intervention opportunities to help a baby's development and any challenges to this following discharge from the unit if waiting for community therapy services where concerns have been highlighted the require quicker access to advise.

"It is hoped that through our connection to Outreach, we will be able to provide an accessible holistic care approach for our pre-term infants and their families even when they have left the unit."
Kiri, OT, Worcester

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"Our babies' being discharged from the neonatal unit is only the beginning of their journey and we hugely value the work that the outreach team do and are happy to be involved in supporting them and our families. Working alongside the outreach team means that our high-risk babies can still access support from the Physiotherapy team once they've gone home, before contact with community services. The outreach team can highlight any concerns they may have or direct questions from parents to the Physiotherapists who can liaise with the team or with families directly. This working relationship is vital to continue to support these babies and optimise their development and long-term outcomes." Zoe, Physiotherapist, Worcester

Speech and Language Therapist

Optimising early communication and feeding opportunities can be supported during the neonatal stay to establish positive communication and feeding experiences which may help a baby's transition to suck feeding and reduce the potential of feeding, communication and interaction difficulties. Prior to the transition to home, a plan can be developed with focus on supporting a baby's communication and suck feeding. Follow up can include liaison between families, the outreach team and the speech and language therapy team to monitor and support a baby's feeding and communication development and progress. On discharge from outreach services, speech and language therapy can ensure referrals to the appropriate community speech and language therapy teams.

"Babies who have been seen by Speech and Language Therapy on NNU who are discharged home with continued feeding difficulties have been provided with ongoing advice and support through collaborative working with NCOT. It is so valuable to be able to offer ongoing support so feeding can be established in a more positive, familiar environments with consistent feeders supporting their development. This support has been through discussions together and some telephone reviews with parents. We have jointly supported a number of babies now to work towards more positive feeding experiences resulting in NGTs no longer being used once feeding has established at home." Beth, SALT, Worcester

Dietitian

Identifying early faltering growth is key both on the neonatal unit and in community. Prior to discharge when growth is a concern a plan should be put into place involving the multi-disciplinary team, usually also consisting of SALT and infant feeding lead for lactation advice along with outreach services input. Once in community outreach staff should be skilled at spotting this early and liaising with the dietitian for input to maximise nutrition and effective feeding. In community support can be given to the outreach services team to achieve this, contact with the family either by telephone or joining the family in clinic for paediatric review. If babies are readmitted to the paediatric ward for faltering growth and are still under the care of outreach services the dietitian will be involved to review the baby.

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"We really value and appreciate working alongside NCOT and providing a holistic care approach. NCOT will highlight any infants that require dietetic input once home. This may be babies discharged from other hospitals to the local area or those that require additional support carried through from the ward. We collectively discuss feeding approaches to help promote optimal growth and development."
Chloe, Dietitian, Worcester

Clinical Psychologist

Most families who are struggling with their mental health during their baby's neonatal stay are quickly identified and referred for psychological support. Families who have received this support during their neonatal journey will receive continued contact following discharge usually by telephone but may see the psychologist on the unit if visiting the hospital for follow up. Some parents do not see changes in their mental health until after their baby is discharged. In these cases, outreach services staff can identify parents that would benefit from psychological support either as a new referral or may have had previous input.

"Many families hold it together stress-wise while their baby is actually in Neonatal Services in hospital, but then find that all of the stress and trauma that they have experienced, the whole way through pregnancy, birth and then their time in Neonatal Services, erupts when they get home with their baby/babies. It has therefore been vital that when NCOT are providing continuing health care to their baby/babies within their homes, they are also able to identify these families and signpost them to the appropriate mental health services; I am happy to contact these parents to support them in assessing their needs and finding them the most appropriate resource for what they are experiencing. In time however, I hope that I can work more closely with NCOT to offer training and consultation to help them identify families who are in need of mental health support as we know that parents' mental health hugely impacts on their connection and bonding with their children"
Ann, Clinical Psychologist, Worcester

"Effective collaborative working between AHP's and NCOT ensures an integrated approach to the continuing care for the pre-term infant once home but starts during the baby's inpatient stay. The collaboration of these professionals with their expertise, fulfils the baby's physical requirements, including vitally important developmental care, whilst also supporting the family's emotional and psychological needs." Lara Greenway, Matron for Neonatal Services.

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Dietetics

Role of the neonatal dietitian in neonatal community outreach services

Specialist neonatal dietitians are highly skilled professionals with expertise in optimising nutrition and growth of sick and preterm infants. They provide early nutritional interventions from birth during acute care on a neonatal unit where they assess, diagnose, prevent and/or manage the nutritional challenges that arise. The role of the neonatal dietitian in outreach services is less developed but is evolving over time in collaboration with the Neonatal Community Outreach Nursing Team to meet the specific needs of babies and families during this phase. The recent NNOG survey highlighted feeding and growth monitoring to be the biggest sources of anxiety for families whose babies are being cared for by neonatal outreach teams (Appendix A). On-going and proactive nutritional support, advice and interventions from neonatal dietitians working collaboratively within outreach services will reduce and alleviate these parental concerns and support resolving any nutrition related clinical concerns.

Although there has been significant investment in neonatal dietetics within the UK (Mainly in NHS England) this has been focused on the provision of inpatient services and does not extend to providing outreach support. This means that any existing unit neonatal dietetic services are often stretched to provide outreach care, or these babies may be referred to paediatric dietitians who often have limited capacity & skills to manage this caseload appropriately and in a timely manner. To facilitate the development of the specialist neonatal dietetic outreach role, financial resource is required to extend capacity of the existing neonatal dietetic workforce. To support this expansion of role a national dietetic framework for outreach and follow up care is under development (October 2024) by Neonatal Dietitians interest Group (NDiG). It is essential to liaise with local dietetic teams to ensure appropriate commissioning of dietetic services for new or expanding outreach teams.

The table below highlights current examples of good practice demonstrating how neonatal dietitians are developing innovative roles within outreach services, using their time efficiently to meet the needs of babies and families transitioning to home. However, this part of the caseload is an unfunded pressure which can leave the dietetic support the outreach service receives vulnerable and unsustainable. Further data needs to be collected and analysed on dietetic activity in this area of practice as neonatal community outreach services evolve and grow.

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Table 5: Examples of how neonatal dietitians in the UK are providing dietetic input to support neonatal outreach services and the benefits they offer

Examples of the neonatal dietetic role in outreach services	Benefit
Pre discharge	
The neonatal dietitian provides weekly reviews for complex babies/families to prepare for home.	This allows expectations to be set when baby and family are cared for within outreach.
Collaboration of the neonatal dietitian and NCOT to develop a management plan pre discharge for babies going home early with an NGT in place.	Facilitates an earlier transition home from acute care to enable families and babies to receive care in their own home with NCOT support.
NCOT and dietitian review babies together prior to discharge home and provide relevant patient information and agree next steps in care plan.	NCOT and dietitians support the families to understand the next stages for home from a growth and nutrition perspective.
Community Ward Rounds/ MDT discussions	
Attendance at weekly or fortnightly community ward rounds with NCOT and other staff (eg Infant feeding advisor, psychology, medical team etc) to discuss case notes which includes nutrition and growth for babies/families on the outreach caseload.	Dietitians provide a consult based on information for babies/families provided by NCOT in addition to growth chart review. This may be all that is needed to guide NCOT to support the baby/family with nutrition issues without having to involve the dietitian directly. If required, formal/direct dietetic referrals can be made at this time also.
Work closely with NCOT to wean babies off NGT feeds at home while supporting appropriate growth.	Some babies can wean off NGT feeds with NCOT support alone but some may require additional support in collaboration with the dietitian as well as speech and language therapy.
Specialist clinics	
Dietetic attendance at a weekly Neonatal Outreach Wellbeing Clinic to provide a 'one-stop-shop' for babies and families to access the support they need post discharge.	This has been seen to have multiple benefits. For health care professionals it optimises multidisciplinary team working and communication as well as reducing travel time for professionals covering a widespread geographical caseload. For families, it reduces the number of health care related appointments and outpatient hospital attendances and provides opportunities for families to socialise together and give and receive informal peer support.
Supporting Nutrition care indirectly via NCOT home visits	
Co-develop nutrition checklist with NCOT to gather nutrition and feeding information from families 4- 7 days post discharge when NCOT visits them at home.	As the dietitian does not have the capacity to visit babies/families at home this allows NCOT to not only continue to be the consistent source of information and support the family but also ensure that the dietitian has the correct information available to advise during a team review meeting without the need to get directly involved.
Work closely with NCOT to wean babies off NGT feeds at home while supporting appropriate growth.	Some babies can wean off NGT feeds with NCOT support alone but some babies may require additional support in collaboration with the dietitian.
Supporting literature/education	
Development of information leaflets for families and local protocols to support post discharge fortifier use.	Ensures appropriate and consistent use of fortifier post discharge and ensures that families and staff understand how to use this product safely.
Development of specific post discharge	Supports NCOT services to be updated by experienced

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nutrition teaching programme/ webinars for all NCOTs in the region.	neonatal dietitians on the latest evidence, sharing knowledge and skills, as well as local audit data on optimising nutrition during the outreach period. Standardising quality of care across the Region/ Network.
Co- developed protocol for discharge with NGT.	This has enabled infants to get home sooner and establish breast/bottle feeding.
Co-developed protocols on post discharge formula use and vitamin/iron supplements.	This encourages appropriate use of specialist formula and additional supplements.
Co-developed a series of videos with NCOT to educate parents.	Topics included feeding, communication, skin to skin, nutrition and development. This can be accessed by the parents via QR codes.
The dietitian is a member of a short life working group to develop and establish criteria for early home tube feeding to support earlier transition to home.	The Dietitian collaborates with nursing and medical colleagues to update current guidance and establish consensus.
Development of a monthly discharge planning focus group. This involves Allied Health Professionals, Infant feeding Advisor, Charge nurses, staff nurses, nursery nurses and NCOT.	The aim of this group is to enhance the discharge process to ensure a streamlined transition for babies and families. The group focuses on 4 main outcomes: improving compliance with staff, completing discharge checklist, reviewing feedback from family questionnaires, review of Parent Craft Group and home NGT feeding.
Audit	
Gathering and analysis of data on local nutrition protocols.	Review of growth and nutritional intakes based on local or national protocols/guidance allows practice to be evaluated and improved eg post discharge multi-nutrient fortifier protocol .

Occupational Therapy

The role of neonatal occupational therapist in neonatal outreach

Occupational therapy services within neonatal settings are focused on supporting the development of the high-risk infant and their family. Occupational therapists work collaboratively with the neonatal team, (including other AHP's) and parents of high-risk infants to facilitate the infant's and parents' occupational roles, support the parent–infant relationship and ensure a successful transition from hospital to home and community. In addition, occupational therapists contribute to the provision and promotion of developmentally supportive care of high-risk infants. This approach serves to minimise the potential for harm of the neonatal unit environment on the infant's developing brain; supports their growth and development, as well as promoting early engagement with their parents, including co-occupations such as nurturing touch, handling ,feeding, sleeping and bathing RCOT 2022 Occupational Therapy in Neonatal and Early Intervention Services; Practice Guideline (2nd Ed). RCOT.

The scope of the Occupational Therapy role within Neonatal Outreach

During neonatal outreach stage of care, Occupational Therapists implement neuro-behavioural assessment and intervention to help parents read their infant's behavioural cues in order to promote self-regulation and co-occupations e.g. sleep, feeding, play and interaction. Many parents/caregivers experience issues around psychological adjustment following the trauma of a neonatal admission and this is especially the case if their infant has a potentially emerging diagnosis. Some parents will require support and guidance on developing their confidence in understanding and managing their infant's needs while they adapt to life beyond the hospital. Occupational therapists approach this holistically by supporting parent-infant interactions, scaffolding parental confidence and well-being, in addition to providing anticipatory guidance to promote optimal neurodevelopmental outcomes. This early intervention can avoid an escalation to Community

Therapy services. Where a community referral is necessary Occupational Therapists have further links to community services for supporting any ongoing/highlighted developmental needs as part of an AHP team.

Although not an exhaustive list, the following is a list of examples from Occupational Therapy practice guidelines and clinical practice which suggest that an Occupational Therapist may:

- Provide sensitive and appropriate support to enable family in their infant's care and to facilitate parental learning about their infant both during and following the transition to home.
- Provide parent/caregiver support to address any adjustments they can make to promote their own occupational engagement and participation within activities with their infant.
- Use a neuro-behavioural approach to enable the baby to achieve optimal physiological, motoric, organisational and attentional stability (state regulation) during co-occupations such as feeding, sleep, bathing and play.
- Enhance opportunities through developmentally appropriate meaningful co-occupations for parent-infant attachment and bonding.
- Advise around modifying the sensory environment e.g. minimising auditory and light input as well as position changes to promote infant self-regulation therefore readiness for occupational engagement and participation in occupations such as feeding, cares and early interaction.
- Provide anticipatory guidance to support optimal infant neurodevelopment as part of an MDT.
- Suggest adjustments to the position an infant and parent adopt together during early attunement moments to enable both to be comfortable and ready for moments of interaction.
- Recommend use of specific sensory-sensitive handling and positions during early activities to enable the infant to achieve optimal physiological, motoric, organisational and attentional stability (regulation) e.g. modelling use of identified soothing strategies for parent/caregiver to support their baby's regulation during a nappy change.
- Provide, model and facilitate family integrated interventions around positive developmentally appropriate sensory experiences to promote presenting stability, and neurodevelopment e.g. adjusting speed and hand placement during position changes and use of positive touch interventions e.g. massage (where additional specialist training has been undertaken) to promote state regulation and readiness for dressing/undressing.

Physiotherapy

The role of physiotherapy in outreach care

Physiotherapy in neonatal outreach care has a vital role to play in optimising the overall development of the high-risk preterm baby and supporting/ empowering families to enable them to carry out individualised therapy programmes to enable this to be achieved.

Moving from the hospital setting to the home environment as has been mentioned earlier in the framework causes parents stress and worry as well as the excitement of finally having their baby at home. Within most units due to no AHP services being part of outreach care there is a current expectation that parents can adjust to this change and still feel able to continue with therapy programmes without professional support which can be both daunting and challenging. Physiotherapists working within outreach services can help to support this gap by offering appointments to parents in the home environment to look at the challenges and concerns they have once in their home environment and help scaffold parent-infant interactions within the home setting enabling them to feel confident in aspects of their babies care such as handling/positioning and play.

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Within the UK there are currently only a few units who are able to offer an outreach physiotherapy service separate to the routine follow up clinics which we know are variable across the UK as they currently stand. One example of where services involving AHPs have been set up is at East Kent Hospitals University Foundation Trust, where Emma Cave, AHP Lead and Clinical Lead Physiotherapist has been providing in-patient and advanced neurodevelopmental follow up for over 12 years. A pilot Outreach service was set up four years ago which was run by the neonatal nurses. At this time, Emma developed the therapy service in response to the need of the gap that existed between follow up provision and discharge from hospital. This provided support for the babies, families and colleagues on the Outreach service. The nursing Outreach pilot ended, but the enhanced therapy provision has remained.

Following a successful business case, the AHP team has expanded. Emma and her team of an Occupational Therapist and Speech and Language Therapist are now able to offer at least one home visit at about 3 weeks post discharge to support parents with early activity ideas and look at equipment and toys they have in the home. They also support them with more holistic things such as discussing feeding and weight gain. They directly refer into the Neonatologists for review of medication etc as needed. A comment from one parent at her two-year review was that having Emma visit the home had led to a totally different and more positive outcome for her child. The baby had been struggling with feeding and weight gain and had dropped over 3 centile lines with subsequent deleterious effects on development. This was identified and urgent referral to the neonatologist and dietitian made.

Emma also feels that offering parents this earlier visit helps parents adjust to being at home with their baby, providing an invaluable opportunity to discuss all aspects of the baby's development. Explanations around early intervention can be explored, practical ideas and skills developed and the parents have the opportunity to ask questions, helping their baby progress away from the noise and all the distractions of the unit itself.

Examples of the benefits neonatal physiotherapists expected such a service to have included:

- The continuation of early intervention programmes started with parents and babies on the unit, developmental play within the home environment.
- Reassurance to parents.
- Education to neonatal outreach staff.
- Relationship anticipatory guidance support.
- Bridging the gap between discharge from the unit and follow up provision whether from the community therapy teams or the hospital team.

Psychology

(See Appendix L)

The role of psychology working in neonatal outreach

Cornwall Pilot: Psychology working alongside outreach teams

In Cornwall the Psychological Professional has been working with nursing and AHP colleagues to shape the development of a new outreach service, and to provide limited clinical as well as consultation and educational input into that service. The time allocated has been 1 or 2 half days per month.

Service offer so far:

- Working with MDT colleagues to create outreach wellbeing clinics which are psychologically and service user informed.

- Planning psychoeducation and support sessions to families as part of the outreach wellbeing clinic offer.
- Focus on continuing engagement and case management of vulnerable families, such as bereaved families and those at raised risk of mental health decline.
- Joint MDT case working, for example where there are psychological factors influencing the care of their infant (e.g. with feeding).

Anticipated added value to the families and service:

- Continuity of service with appropriate risk assessment and management for vulnerable families (e.g. those with complex mental health histories).
- Overcoming psychological barriers to empower parents and build parental efficacy; potentially reducing demand on further paediatric inpatient or universal services.
- Offering an opportunity for some parents to reflect back on their experience of being on the NNU from a psychologically safer position of having been discharged; with the hope that this processing will be protective against psychological consequences of trauma.
- Supporting families with the transition to home and engagement with outreach as well as universal services.

Hopes for future development:

With further psychology resource plans for further psychologically informed outreach work could include:

- Supporting the start of a psychologically informed peer support group for neonatal families, in partnership with a 3rd sector peer support organisation.
- Focussed one off psychoeducation groups for families under the care of neonatal outreach.
- The psychologist would join the rest of the outreach team in the hoped for increase in clinic locations to improve access for families, who face challenges in terms of rural location and associated scarcity of transport links.

To create a more effective and seamless experience for families as their needs evolve, by increasing links and improving pathways with other statutory and voluntary sector organisations, many of which are co-located with the outreach clinics in ‘family hubs’.

Speech and Language Therapy:

The scope of the Speech and Language Therapy role within Neonatal Outreach

SLTs working together with neonatal outreach teams can support, collaborate closely and empower parents, caregivers and their babies through the transition from the neonatal unit to home. These roles include:

- Education on communication, interaction and language, and feeding development associated with prematurity/neonatal health conditions to help guide parents and caregivers after transition to home.
- MDT post-discharge developmental support of the impact of prematurity and/or health challenges with SLT focus on communication, interaction and language, feeding and weaning
- Ongoing support to parents, caregivers and the neonatal MDT outreach team with the transition from the tube to oral feeding, supported by a cue based responsive feeding approach, and the assessment and management of identified ongoing or emerging feeding difficulties
- Collaborative working with the neonatal MDT, neonatal community outreach teams and community healthcare teams to counsel parents and caregivers if their baby needs to use alternative supplemental feeding methods in the longer term

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- Discussing onward referrals and processes to relevant community teams including SLT if required

The scope of SLT support and services will depend on each neonatal outreach teams service model and delivery, the duration families remain under outreach services and the level of SLT funding required and provided.

Example of Service Model for SLT working in Neonatal Outreach (taken from Thames, Valley and Wessex SLT Service)

Oxford SLT outreach feeding service overview

The Oxford neonatal SLT team currently provide an outreach service for infants and families that have spent time on the neonatal unit. This service is provided out of inpatient NNU SLT time to infants with an Oxfordshire GP:

- Up to 8 weeks corrected age known to SLT on the neonatal unit.
- Infants referred by 6 weeks corrected by neonatal outreach nursing or neonatal Consultants for triage , advice and referral on to community SLT if required.
- Up to 6 months of age for infants with T21, TOF/OA who have spent time of the neonatal unit.
- Families attending the monthly therapies run group Little Saplings (often also seen by community if complex needs once over 8 weeks).

Outreach patients may be seen:

- In the SLT outreach clinic (Fri pms)
- As part of MDT assessment at the neonatal follow up clinics
- On the childrens wards if transferred from NNU to childrens hospital
- At Little Saplings group

The SLT outreach service age criteria for referral was reduced from 6 months to 6 weeks in 2022 due to the large and growing caseload which was having a significant impact on inpatient SLT availability and responsiveness. Around 20% of the neonatal SLT funded time is spent on outreach currently (0.2 wte). There is no ringfenced funding for neonatal SLT outreach and no funding for the neonatal service to support preterm or complex infants on TC/ postnatal wards.

Phone contact with a family for initial discussion, and advice where appropriate, is typically completed within 2 working days of referral with an appointment (telemed or face to face) made within an average of 7 working day of referral. Follow ups are then patient led and comprise of a combination of phone, telemed and face to face reviews and MDT meetings.

Babies are typically seen by the outreach SLT for a range of reasons including prolonged feeding times, signs of swallow dysfunction, differential diagnosis of reflux vs swallow dysfunction due to immaturity or structural reasons, tongue tie assessment, transition from NGT to breastfeeding/bottle feeding support (SLT is also IBCLC), oral aversion or risk of, supporting parents to understand communication in relation to feeding, complex neurology), weaning support for those infants not following typical solids transition pathway.

Approximately 60% of these families require further onward referral to community SLT services where they will be seen within 3-7 weeks of referral and thereon approximately every 3-8 weeks depending on need.

Co-dependencies

Some babies that have been seen by SLT on the neonatal unit and do not have a dysphagia but may

have some persisting feeding difficulties including prolonged tube weaning may be seen by the SLT in outreach clinic if there are numerous medical comorbidities but if less complex feeding challenges SLT will often ask the nursing outreach team to monitor feeding closely with specific areas highlighted for concern e.g. support with specific positioning. This reduces the number of appointments families have to attend but may place additional burden on the outreach team or missed signs of feeding difficulties if visits do not coincide with outreach nursing visits. This is more frequently the case as the outreach nurses caseload pressures are increasing with increasing demand and patient complexity. The outreach nurses do also have easy access to the neonatal team for advice which in some cases has meant that referral for formal SLT assessment has not been required enabling a cost saving for services and families. The SLT will liaise closely with the outreach nursing team around any shared patients enabling coherent shared care and collaboration and SLT may get weights for the outreach team when the baby comes to clinic or the outreach nurses may introduce a piece of equipment or a technique advised by the SLT during their visit to be reviewed at the next SLT clinic review to enable consistent progression of a feeding plan.

The babies who require both tube feeding support and oxygen support at home however are transferred to the community nursing teams at the point of discharge from the neonatal unit. Typically these have been the babies with the most complex needs, perhaps born the earliest hence their delayed readiness for sucking feeds, at higher risk of swallow and oral motor dysfunction and more likely to have a persisting oxygen requirement due to ELBW. For the SLT this has posed a number of challenges as the Oxfordshire community nursing (CCN) teams do not have expertise in preterm infant development and care is less joined up or missing as the CCN teams do not visit often, only if there is a specific issue with relation to the NG tube having come out, equipment supplies or safeguarding.

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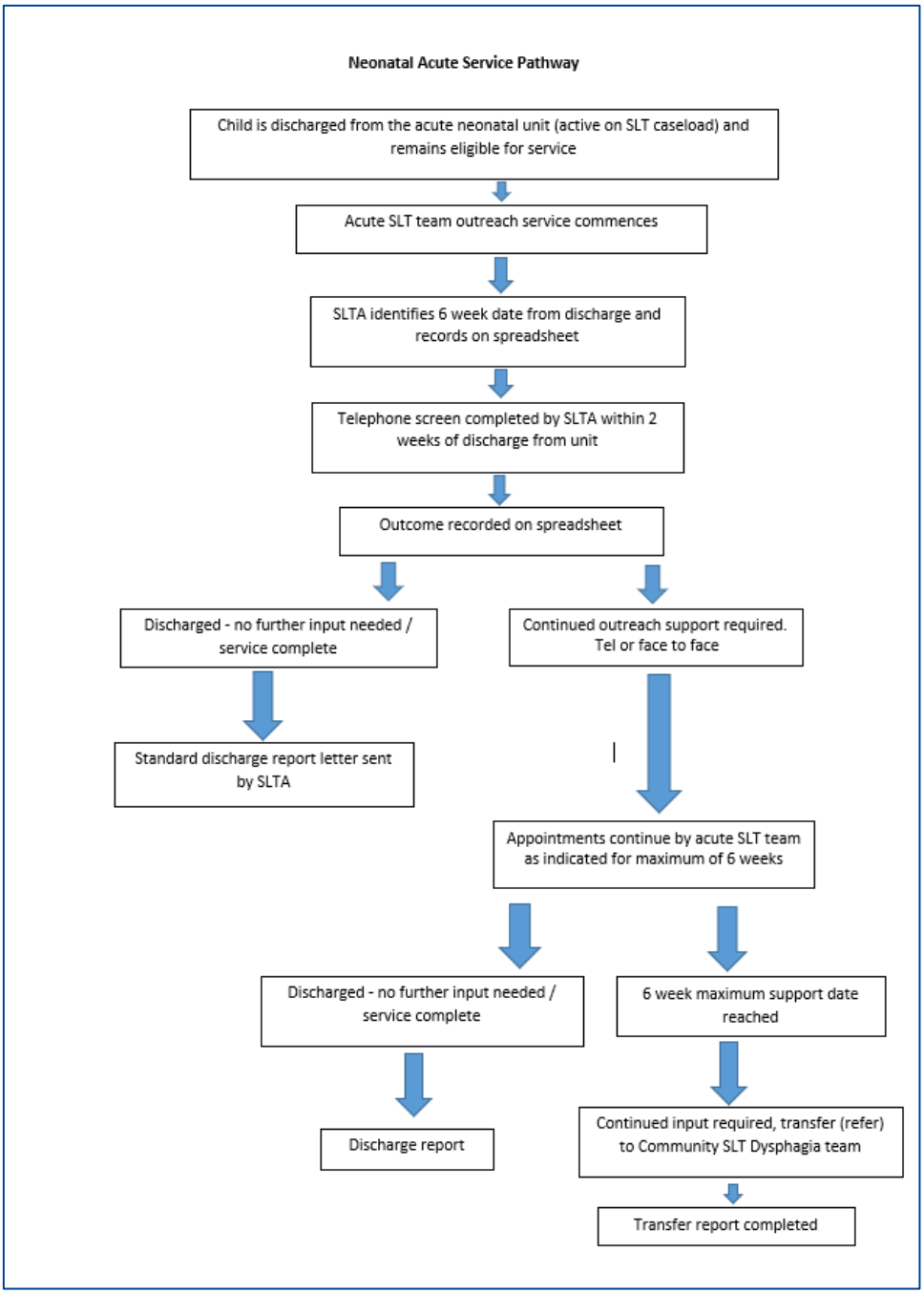
Fig 1: Example of Acute SLT Neonatal Outreach Service Pathway, NHS Trust based in West Midlands



Case Study of SLT Input

Level 2 Unit, Protected outreach time			
Baby born at 30+5, discharged home bottle only at 36 weeks			
Date	**Event**	**Outcome**	**Action**
2.2.2024	Discharged home	Added to Speech and Language Therapy Assistant (SLTA) outreach list	SLTA to complete tel screen
8.2.2024	SLTA completed telephone screen	Face to face review appointment needed	Clinic appt offered 22.2.2024 with SLT
22.2.2024	Clinic appt with SLT	Advice provided, updated NCOT, referred to tongue tie team	Tel review 1 -2 weeks with SLT
6.3.2024	Telephone review with SLT	Frenulotomy completed 5.3.24	Joint clinic review with NCOT 7.3.24
7.3.2024	Clinic appt with SLT and NCOT	Review completed	Discharged from SLT
8.3.2024	SLTA completed spreadsheet	Discharge report generated	Discharge report sent by SLTA
Summary of input: 1 x tel screen, 2 x clinic appt, 1 x tel review. Length of input: 5 weeks. Combination of SLT and SLTA.			
Problems avoided: readmission due to reflux symptoms increased+, able to offer advice to manage presentation			

Level 3 Unit, No outreach			
Baby born at 24+4 , discharged home breast and tube at 42+6 under NCOT service			
Date	**Event**	**Outcome**	**Action**
10th May 2024	Advice requested from NCOT – tube removed, short breastfeeds, aspiration concerns with bottle feeds and weight loss.	Joint feeding plan made with NCOT, Dietetics and family. Tube re-passed, asked to stop bottle feeds, focus on breastfeeds using assessment chart and NGT top ups.	Contacted community SLT to update with information to add to referral already made. Waiting list for high risk currently 18 weeks.
Summary of input: 1 tel contact with parents, 1 tel contact with SLT community, 1 face to face contact and advice with NCOT.			
Short term plan to support feeding and nutrition in place but highlighted family needed immediate SLT and Dietetic input at home due to on-going feeding difficulties related to extreme prematurity.			

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Appendix K: Suggested resources for parent-infant relationship, parental confidence and parental mental health

- Keritane Parenting Confidence Scale

  Črnčec, R., Barnett, B., & Matthey, S. Development of an instrument to assess perceived self-efficacy in the parents of infants. Research in Nursing & Health, 2008, 31(5), 442-453. DOI: 10.1002/nur.20271.

- Lanarkshire Indicator Set https://www.nhslanarkshire.scot.nhs.uk/download/imh-observational-indicator-set-interactive/

- The Postpartum Bonding Questionnaire
  Brockington IF, Fraser C, Wilson D. The Postpartum Bonding Questionnaire: a validation. Arch Womens Ment Health, 2006, Sep;9(5):233-42. DOI: 10.1007/s00737-006-0132-1. Epub 2006 May 4. PMID: 16673041.

- Mother's Object Relations Scale
  Rosenberg, R. The Mother's Object Relations Scale: A measure of maternal object relations. Journal of Clinical Child Psychology, 1986,15(2), 137-145. DOI: 10.1207/s15374424jccp1502_2

- CORE10
  https://www.coresystemtrust.org.uk/wp-content/uploads/2020/08/CORE-10_English_fillable_optional_items_minimal_header_buttons.pdf

- Perinatal PTSD Questionnaire
  Komurcu Akik B, Durak Batigun A. Perinatal Post Traumatic Stress Disorder Questionnaire-II (PPQ-II): adaptation, validity, and reliability study. Dusunen Adam The Journal of Psychiatry and Neurological Sciences, 2020;33:340-350.

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Appendix L: Staffing recommendations for psychological professionals for outreach and follow up care

Table 6 shows the staffing required to achieve this outpatient support at the three outlined levels.

Table 6: Staffing specification (per unit – *outpatient based)

Unit level	Staffing for specialist psychological provision (per unit)[1,2]	Hub provision[1,3]	ODN lead psychologist provision
LNU (Level 2) and NICU (Level 3)	1–1.5 WTE Band 8a psychological professional	An additional 0.2 WTE Band 8b/c (per hub – shared across unit levels 1,2,3* (0.6 WTE per hub when combined with inpatient standards)	0.3 WTE per 10,000 births across the network (Network wide provision for both inpatient and outpatient psychology services)
	1 WTE Band 5 assistant psychologist		
SCU (Level 1)	0.5–1 WTE Band 8a psychological professional		
	0.5 WTE Band 5 Assistant Psychologist		

LNU: Local Neonatal Unit; NICU: Neonatal Intensive Care Unit; ODN: Operational Delivery Network; SCU: Special Care Unit; WTE: whole time equivalent.
[1]This provision is in addition to inpatient staffing
[2] Where there is high complexity in the outpatient population (eg., complex psychological or medical needs, high levels of deprivation in the area) this higher level of staffing provision may be required
[3] This is based on 2–3 hospitals per hub. If the size of hub is larger, provision will need to be calculated on these figures to adequately meet local need.

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