

Name of Organisation: British Association of Perinatal Medicine (BAPM)

Contributing Organisations in Addition to BAPM

- Bliss
- British Dietetic Association, Neonatal Dietitians Group (NDiG)
- National Neonatal Surgical Interest Group (NNSIG),
- Neonatal Committee of Association of Paediatric Chartered Physiotherapy
- Neonatal Dietitians Group (NDiG),
- Neonatal Leads for Psychological Practice (NeoleaP)
- Neonatal Nurses Association (NNA)
- Neonatal & Paediatric Pharmacy Group (NPPG)
- Neonatal Transport Group (NTG)
- Networks Neonatal Outreach Group NNOG
- Royal College Speech & Language Therapy, Neonatal Clinical Excellence Network

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

We need the full implementation and funding of all the recommendations of the Neonatal Critical Care Review (NCCR) published in 2019¹ and the recent House of Lords Preterm Birth report² and the Neonatal GIRFT review³. The NCCR has helped to transform neonatal services by ensuring appropriate staffing standards and continuing the centralisation of neonatal services, which will improve outcomes and safety, however, many recommendations have not yet been fully funded.

This includes the following:

1. Staffing

The neonatal workforce is made up of nurses, doctors, allied health professionals, psychologists, pharmacists and other healthcare professionals. These are vital to providing safe and effective neonatal care. Sufficient workforce is important, but retention of staff is also vital. To maintain retention, staff need to feel valued.

Nurses: At present the neonatal workforce is commissioned for 'cot side' nurses only. Neonatal Transitional Care (TC) and Neonatal Outreach should also be commissioned (see Q2) to facilitate earlier discharge.

Nursing roles such as education, governance, family care (including bereavement and palliative care), quality improvement, infant feeding specialist, neonatal surgical nurses/surgical outreach and research are also essential to support quality care and improve outcomes and will also improve the career pathway and retention.

¹ Implementing the Recommendations of the Neonatal Critical Care Transformation Review, NHS England, 2019 Available at: https://www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf

² Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024

³ Neonatology, GIRFT Programme National Speciality Report April 2022



Action: TC and Outreach and other specialist nursing posts need to be commissioned and funded.

Medical: The biggest gap in workforce provision is in the neonatal medical workforce. This was highlighted in the GIRFT Neonatal medical workforce report⁴. This highlighted significant pressure on the whole of the neonatal workforce with shortages in medical, nursing, allied health professionals (AHP) and psychology in England.

It found that NICU compliance with medical standards⁵ varied between 70% in high-volume NICUs and 19% in low-volume NICUs. The lack of 12-hour consultant presence was the main reason for non-compliance. In local neonatal units (LNUs) lack of rota separation from general paediatrics at tier 1&2 were the main reasons for non-compliance. Vacancies against budgeted establishment were present in all units. Difficulty filling deanery training posts was the most common reason for vacancies. There is variation both in the number of medical personnel available to support neonatal care where activity levels are similar, and in the roles and responsibilities undertaken by medical staff or other staff groups across different services.

Action: Analysis of the reasons for these gaps is required and a clear medical workforce plan for neonatal services needs to be developed.

Allied Health Professionals (AHPs): There is increasing evidence and awareness of the benefit on outcomes, AHPs contribute to neonatal care particularly for the support of parents. This group includes dietitians, occupational therapists, physiotherapists and speech and language therapists. Following recommendations from the NCCR⁶, NHSE provided dedicated funding for AHP posts within acute neonatal services. Despite this funding, there is a continuing workforce deficit across all AHPs of 68% in comparison to published workforce recommendations^{7,8}.

Action: Work is required to understand the reasons for these difficulties and to improve recruitment and retention.

Adequate funding, resources, training & career pathways are required to fully embed AHP service in teams in line with published workforce recommendations including collaboration with Higher Education Institutions (HEIs) to ensure curriculum content and projected workforce numbers are in line with the anticipated demand.

⁴ Neonatology – Workforce GIRFT Programme National Specialty Report. Eleri Adams, Kelly Harvey, Michelle Sweeting. April 2022

⁵ BAPM (2021) Optimal Arrangements for Neonatal Intensive Care Units in the UK; https://www.bapm.org/resources/296-optimal-arrangements-for-neonatal-intensive-care-units-in-the-uk-2021

⁶ Implementing the Recommendations of the Neonatal Critical Care Transformation Review, NHS England, 2019 Available at: https://www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf

⁷ BAPM AHP standards

⁸ Neonatal Critical Care Service Specification. NHS England March 2024. <u>Neonatal-critical-care-service-specification-March-2024.pdf</u>



Pharmacy: Standardisation of prescribing and administering complex intravenous, continuous drug infusions, and the development of Smart Infusion Pump datasets, are essential for the pharmaceutical development and safe administration of ready-to-administer medications for the neonatal population (see later under Q3).

This is a big change in practice for individual neonatal units. Implementing standard intravenous continuous drug infusions in practice needs to be supported by neonatal network pharmacists. There is currently an unequal distribution of network pharmacists across neonatal ODNs in England – only 6 out 11 have network pharmacists in post. There are different employment arrangements at each neonatal ODN, which leads to an inequity in services which needs to be addressed.

Action: Work is required to understand and rectify the differences in pharmacy provision between networks.

Psychology professionals: The NCCR also funded network lead psychologists as well as some hub posts (covering an LMNS footprint) and in-unit psychologists. Psychologists support the wellbeing needs of infants, families and staff and develop culture and psychological safety across neonatal units, vital following a number of high-profile reviews highlighting issues with team functioning and dynamics as key in serious incidents including deaths of mothers and babies.

Overall, there remains a 70% gap against staffing standards for psychological professionals which reduces the capacity of psychological professionals to deliver the service, presents a risk to safety and a long-term cost to the NHS in terms of psychological sequalae of neonatal graduates, parents and staff. Psychological professionals not only mitigate the harm and distress of neonatal admission, but support and prevent further difficulties. They also have a positive impact on neonatal staff sickness absence and retention rates so represent a cost saving when psychological professionals are fully recruited against staffing standards.

Action: Work is required to understand why there are gaps in provision and to rectify these.

Staff Development

Development, recruitment and retention of staff in neonatal services is important in order to be able to continue to provide and maintain optimal staffing. In addition, data from NHS staff surveys⁹ across maternity and neonatal services identifies a culture of staff feeling unheard and practising in fear. Processes for whistleblowing and raising safety concerns are viewed as ineffective. BAPM has recently published a framework about raising concerns in neonatal services¹⁰.

There are a number of things which could be done to facilitate this:-

⁹ National results across the NHS in England | NHS Staff Survey

 ¹⁰BAPM How to Raise a Concern: A Guide to Whistleblowing for Neonatal Healthcare Professionals. July
2024 https://hubble-live-assets.s3.eu-west-

^{1.}amazonaws.com/bapm/file_asset/file/2729/How_to_raise_a_concern.pdf



- a.) A full NHS bursary is key to increasing registration onto university nursing degree courses (and lessening attrition). Trainee nurses can be eligible for £5k but it is means tested. These trainee nurses must work more hours to achieve their clinical expectation, therefore they are unable to work outside of their course to support their degree.
- b.) Funding Nursing Apprenticeships as a route into neonatal nursing. This will support current ancillary staff to progress to registration and will support succession and retention of staff.
- c.) Availability of training for all staff is important. This needs to be protected time for training and it needs to be funded and equitable. This should include support for all newly qualified professionals especially in the first five years with quality inductions and preceptorship support, initiatives to improve alternative access to education including apprentices and support for nurses AHPs and medical staff.
- d.) Training is also vital to improve safety. A recent BAPM Framework on Airway Safety Standards¹¹ highlighted experience in intubation amongst neonatal professionals has decreased because of changes in clinical practice and changes in arrangements for training. Problems with intubation have been identified by HSIB as significant issues resulting in patient harm¹². Ensuring airway safety is therefore vital. Providing this training requires time and resources to deliver the training and to free up staff to receive it.
- e.) To support recruitment and retention career progression within neonatal nursing is key. This is an expert workforce who must be nurtured and encouraged to develop through structured succession planning from undergraduate, post-graduate, QIS, ENNP, ANNP and Consultant Practitioners, alongside the quality roles. The National GIRFT report in collaboration with the NNA set out a clear career structure for neonatal nurses.
- f.) Neonatal care would become more attractive as a career and retain more staff if the increased level of expertise and responsibility of neonatal nurses were recognised in a similar way to that of midwives, that is, on completion of their qualification in speciality (QiS) they should progress from an Agenda for Change band 5 to band 6 following a period of consolidation as per recommendation 3 in HEE's Neonatal Qualified in Specialty (QIS) Education and Training Review. Currently, there is inequity, and nurses will move to other specialties where they are appropriately recognised.
- g.) Allied Health Professionals: Adequate funding such as bursaries and apprenticeships will entice more people to consider neonatal allied health professions as a career option. To reduce staff turnover, maximise retention and provide an attractive clear career pathway funding is required both at HEI and Unit level.

Action:

¹¹ BAPM Airway Safety Standard A Framework for Practice April 2024. <u>BAPM Neonatal Airway Safety Standard | British Association of Perinatal Medicine</u>

¹² Thematic Analysis of Neonatal Resuscitation in Term Neonatal Brain Injury and Early Death in England HSIB presentation at neonatal society. Nov 2024. Bowman et al.



Provide a full NHS nursing bursary for student nurses and AHPs.

Fund nurse apprenticeships as a route into neonatal nursing.

Provide protected time for training for all neonatal staff

Provide the time and resources to deliver simulation training particularly airway training for neonatal medical staff.

Establish a uniform career structure and progression for neonatal nurses.

2. Cot Capacity

A partly centralised model using Neonatal Networks has been developed in England and Wales because being able to care for the smallest and sickest babies in the right place is vital to improving outcomes. There is good evidence that outcomes are better when these babies are cared for in larger NICUs¹³. The NCCR helped to provide some additional capacity however it was limited because of a lack of capital funding required for the required changes in some regions. Completing this work to ensure that the care of all babies in every network can be optimised is essential.

The new hospital programme is very important to neonatal services. A number of hospitals have poor facilities and estates affecting their neonatal services. It is important that these issues are addressed allowing expansion of neonatal capacity where required. It is also important that services are correctly configured with neonatal intensive care co-located with other children's services where possible particularly paediatric surgical services.

Action: Ensure sufficient cot capacity in every network by completing capacity work.

3. Parent Support and Family Integrated Care

Having a baby admitted to neonatal care is a disruptive and distressing experience, and one in which parents need access to the support to enable them to be partners in their baby's care. This approach, 'Family Integrated Care' (FIC), has been shown to provide short-term and long-term benefits to babies – including a shorter length of stay and improved developmental outcomes as well as improved parental mental health and family attachment and bonding¹⁴.

¹³ Implementing the Recommendations of the Neonatal Critical Care Transformation Review, NHS England, 2019 Available at: https://www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the-Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf

¹⁴ O'Brien et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, Lancet Child Adolesc Health, 2(4):245-254



To deliver FIC, there is an urgent need for better provision of parent accommodation and facilities to enable parents to be on the unit with their baby as much as they need to 15,16. Accommodation provision varies significantly, and can be a barrier to parental involvement in care.

Parental accommodation has previously been identified as a priority and of significant importance in previous reviews¹⁷, ¹⁸, ¹⁹. The House of Lords Report²⁰ stated NHS England should publish the findings of its maternity and neonatal estates survey, setting out what proportion of neonatal units are currently able to provide sufficient accommodation for all families, as per the updated service specification for neonatal critical care. The requirements to meet standards can then be assessed and where possible these should be resourced.

Action: NHS England should publish the findings of its maternity and neonatal estates survey, setting out what proportion of neonatal units are currently able to provide sufficient accommodation for all families, as per the updated service specification for neonatal critical care²¹ and create a plan to remedy this.

4. Addressing Inequalities

Significant inequalities have been identified in provision and outcomes from maternity and neonatal care which need to be addressed. Appointing a National Neonatal Safety Champion could drive improvements in safety, with a substantial focus on health inequalities²²

In addition, it would be useful to focus the next phase of the Cultural Leadership programme specifically on the provision of culturally competent support for families to tackle inequalities in parent experience in neonatal units.

There should be work on developing guidance on joining-up post-natal maternity and neonatal care to support in-patient mothers to be with their babies in neonatal care while also accessing the post-natal care and support they need²³.

¹⁵ Flacking et al (2012) Closeness and Separation in neonatal intensive care, Acta Paediatr, 101(10): 1032–1037

¹⁶ Lehtonen L, Lee SK, Kusuda S, Lui K, Norman M, Bassler D, Håkansson S,Vento M, Darlow BA, Adams M, Puglia M, Isayama T, Noguchi A, Morisaki N, Helenius K, Reichman B,Shah PS, on behalf of the International Network for Evaluating Outcomes of Neonates (iNeo), FamilyRooms in NICUs and Neonatal Outcomes: An International Survey and Linked Cohort Study, of Pediatrics (2020)

¹⁷ Neonatal Toolkit 2009.

https://webarchive.nationalarchives.gov.uk/ukgwa/20130123200735/dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH_107845

¹⁸ Neonatal Critical Care Service Specification. NHS England March 2024. <u>Neonatal-critical-care-service-specification-March-2024.pdf</u>

¹⁹ Neonatology. GIRFT Programme National Speciality Report April 2022

²⁰ Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024

²¹ Paragraph 166 HOL report

²²BLISS https://s3.eu-west-2.amazonaws.com/sr-bliss/documents/Research-and-campaigns/Campaigns/Manifesto-July24-2-Address-inequalities.pdf

²³ https://s3.eu-west-2.amazonaws.com/sr-bliss/images/Research-and-campaigns/Coordination-of-maternity-and-neonatal-care.pdf



Action: Appoint a neonatal safety champion

Focus cultural leadership programme on support for families to tackle inequalities.

Develop guidance to support parents of babies in neonatal care

5. Wellbeing support for staff

Providing neonatal care for babies and families can be stressful and at times distressing. Infants experience pain, stress and distress and parents are often distressed, and manifest this in a variety of ways. Parents have often experienced trauma in their past and during the maternity journey and can also find the neonatal unit further traumatising. Staff need to be able to deal with this and responses may be difficult for staff to make sense of or to bear. Neonatal staff are exposed to media scrutiny and comment and critical public perception on a regular basis, and have to bear the resulting increase in targets, scrutiny and continued pressure from the system they work in.

As a result, staff recruitment and retention can be challenging and there can be high rates of sickness absence in this population. We know that critical care staff are some of the most highly stressed and distressed of any healthcare staff.

To help staff meet the complex needs of babies and families and manage the psychological threats in the system, the response needs to be holistic, and provide universal care to all staff, whether or not they are actively struggling. It needs to encompass good management training and support, opportunities for team training and regular communication, availability of peer supervision (perhaps through the PNA model) and access to psychological professionals, who provide both individual and group interventions, and support the psychological literacy and resilience of the unit as a whole.

There is also a need for high quality staff support services within Trusts offering evidence-based interventions. For this to happen, staff support services should be within the portfolio of the Chief psychological professions officer (CPPO) and this role should be extended to acute trusts from the model found mainly within mental health.

Action: Provide staff support services for neonatal staff

Introducing the three shifts

- Shift 1: moving more care from hospitals to communities
- Shift 2: making better use of technology in health and care
- Shift 3: focussing on preventing sickness, not just treating it

In answering the following questions on the 3 shifts, we'd welcome references to specific examples or case studies. Please also indicate how you would prioritise these and at what level you would recommend addressing this at, i.e. a central approach or local approach.



The next questions relate to 3 'shifts' – big changes to the way health and care services work – that doctors, nurses, patient charities, academics and politicians from all parties broadly agree are necessary to improve health and care services in England:

Shift 1: moving more care from hospitals to communities

This means delivering more tests, scans, treatments and therapies nearer to where people live. This could help people lead healthier and more independent lives, reducing the likelihood of serious illness and long hospital stays. This would allow hospitals to focus on the most serious illnesses and emergencies.

More health services would be provided at places like GP clinics, pharmacies, local health centres, and in people's homes. This may involve adapting or extending clinics, surgeries and other facilities in our neighbourhoods, so that they can provide things that are mostly delivered in hospitals at the moment.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Whilst most of the neonatal intensive care provided needs to be provided in hospital there is significant scope for earlier discharge for some babies if the right resources are in place.

1. Neonatal Outreach Service and Transitional Care

Transitional Care (TC): TC is the care of babies with some additional medical needs with their mothers present and caring for them in a setting outside of the neonatal unit. Using TC can allow babies who would otherwise be admitted to the neonatal unit to remain with their parent avoiding neonatal care days. This is better for the baby and family, makes establishing breast feeding easier and facilitates earlier discharge from hospital. It enables better throughput for neonatal units and avoids costs of neonatal admission.

BAPM TC Framework for Practice²⁴ is a framework for practice for neonatal TC which contains staffing standards and care standards for babies of this type. The type of additional care provided in TC can include NGT feeding, phototherapy, antibiotics and temperature management using hot cots or incubators. Full implementation of this in every hospital providing neonatal care would avoid many admissions and support mothers to be the primary caregiver for babies born 33 -37 weeks gestation, reducing admissions to the neonatal unit.

Action: The requirements for full provision of TC in all neonatal services should be assessed and adequately resourced to ensure provision of this service in every hospital providing neonatal care.

8

²⁴ Neonatal Transitional Care - A Framework for Practice (2017) A BAPM Framework for Practice. <u>Neonatal Transitional Care - A Framework for Practice (2017) | British Association of Perinatal Medicine</u>



Neonatal Outreach: Outreach or Outreach services are the ongoing care provided at home by neonatal services following the discharge of babies from the neonatal unit. This can allow early discharge of babies with safe support in the community.

Outreach services are not currently commissioned. They are provided by many hospitals though and can allow a range of support and services to be provided at home but there are large variations in the provision²⁵. The type of care that can be provided at home may include NGT feeding, oxygen therapy, phototherapy and feeding support.

The experience of being discharged home can be a difficult period for families of babies who have been unwell. Parents must adjust to the fact that they no longer fall within the protective zone of the neonatal unit, even though some will have been discharged home with a baby who remains medically vulnerable. Parents frequently have to manage ongoing medical difficulties or additional care needs, such as tube feeding, after their baby leaves neonatal care. Readmissions to hospital are also common. A 2022 survey of parents whose children had recently received treatment in a UK NICU found that 36% "did not feel that they were well supported with their infant's specialised care needs" following discharge home²⁶

Achieving this could significantly reduce neonatal occupancy and costs. There is, however, currently a perverse incentive to keep babies on neonatal units because of current funding arrangements rather than to achieve earlier discharge.

Commissioning for neonatal services needs to be restructured to include transitional and outreach services medical and surgical which meet BAPM framework standards. It should incentivise earlier discharge (with appropriate safeguards) with appropriately funded multidisciplinary home care teams.

This will ensure babies are cared for in the right place (including at home through virtual wards) by the right people, reducing baby-parent separation, improving outcomes for babies, reducing separation anxiety and post-traumatic stress in parents and reducing length of neonatal stay in hospital.

Specialist mental health and neonatal outreach services can also play a key role in delivering such support. However, these are not always available and there is currently no funded specialist neonatal psychological provision in outreach teams. While health visitors do reach all families, they are poorly equipped to meet the specific needs of preterm babies and their parents due to their limited training on the impacts of prematurity. A specific issue which has been recognised is health visitors lack of knowledge for caring for babies born extremely early. Better provision of Outreach nursing support could enable improved handover of these vulnerable babies to health visitors to improve longer term support for parents of babies born early.

²⁵ Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024

²⁶ Katherine Sabin and Fiona Challacombe evidence given to Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024



NHS England should work with training providers to embed opportunities to develop specialist knowledge of the needs of preterm and other sick babies and their families into health visitor training and continuous professional development, with protected training time.

Action: Commissioning for neonatal services needs to be restructured to include transitional and outreach services medical and surgical which meet BAPM framework standards. Neonatal Nurses need protected time within specific roles to deliver TC and outreach services.

Specialist Neonatal Surgical Outreach Nurses: Babies that require surgery, in the neonatal period, can be the sickest and most complex babies cared for on neonatal units. They can often need several months in hospital. Neonatal surgical special nurses/outreach nurses would facilitate improved patient flow, in and out of tertiary centres and improved patient pathways. They would support the timely transition of some of our sickest babies, to be discharged home or cared for closer to home in local hospitals freeing up beds in NICUs and allowing earlier discharge home.

They can also facilitate parental and staff training to ensure successful discharge/repatriation with ongoing expert support available.

Action: Fund and recruit surgical specialist nurses to facilitate discharge of surgical babies

Shift 2: Analogue to Digital

Improving how we use technology across health and care could have a big impact on our health and care services in the future.

Examples might include better computer systems so patients only have to tell their story once; video appointments; AI scanners that can identify disease more quickly and accurately; and more advanced robotics enabling ever more effective surgery.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Electronic Patient Records Systems

Neonatal intensive care is very dependent on technology including ventilation devices, complex monitoring, temperature control and maintenance. Data recording is essential for monitoring, safety, audit, quality improvement and research and nationally collated data is used to benchmark neonatal services and improve quality.

Nationally reported data is only possible if data are recorded using standardised data definitions. Historically, neonatal services have been fortunate in that a single patient data record system has been used by almost all services (BadgerNet Neonatal, System C).

Hospital trusts now use a variety of different electronic patient record (EPR) systems, and this diversity of provision threatens national data reporting. Existing dataflows can be supported and improved, and the utility of national reporting maintained and expanded by addressing the underlying problems. This requires standardised data definitions, according to a dataset designed for, and controlled by the NHS



which pays for it. EPR providers should be influenced, using the NHS monopoly, to ensure EPRs collect this dataset, and the dataset should be collected, collated and held so that existing uses by audits, benchmarking, research and quality improvement activities can continue alongside other secondary data uses, such as NHSE monitoring neonatal clinical activity in real time. Crucially, functional interoperability between NHS trusts' EPRs should be maintained so that patient data is only entered once for clinical purposes and can then be used by subsequent organisations providing care for a baby, as well as for secondary uses.

Action: It is essential that data systems implement the principle of data entered once and used for multiple purposes. This will avoid the time wasted, and the risk of errors, in duplicated data entry.

Some professionals work between different services and different hospital trusts e.g. psychologists work between mental health trusts and acute maternity and neonatal services. We need electronic systems which communicate to ensure care that has taken place is accessible for all relevant clinicians.

Electronic Prescribing

Most Trusts do not currently have electronic prescribing systems despite evidence that it could significantly reduce errors. This is a particular problem in neonatal services where drug errors are the most frequent safety issue reported²⁷. When electronic prescribing is introduced, systems often do not have the facility for complex neonatal prescribing. More work developing and implementing a uniform national electronic prescribing system into neonatal services is required, so that professional moving between Trusts do not have to use different systems developed by each Trust.

Action: Develop a national electronic prescribing system to be used in all neonatal services

Drug Administration Systems

Standardisation of prescribing and administering complex intravenous continuous drug infusions (and development of Smart Infusion Pump datasets) are essential for pharmaceutical development and safe administration of ready-to-administer medications for the neonatal population. Currently, creating complex data pump libraries within systems such as Smart Infusion Pumps is a resource burden to individual institutions and is open to error. National data libraries need to be produced, and shared and embedded.

This is a big change in practice for individual neonatal units. Implementing standard intravenous continuous drug infusions in practice needs to be supported by neonatal network pharmacists (see above under staffing).

Wireless Monitoring

Development of wireless monitoring systems for preterm babies could help to improve families access to their baby. As stated above there is good evidence that FIC improves outcomes²⁸. More research in this area is required to develop systems which are safe and effective.

²⁷Krzyzaniak N, Bajorek B. Medication safety in neonatal care: a review of medication errors among neonates. Ther Adv Drug Saf. 2016 Jun;7(3):102-19.

²⁸ Family Integrated Care | British Association of Perinatal Medicine



Simulation Training

There are now many high-tech simulation training devices and mannequins available for neonatal training. These devices tend to be expensive. Investment in technologies is required which will facilitate safe essential skills training, particularly in the area of airways skills and intubation which has been highlighted as a significant safety issue²⁹ and where the current models are not sophisticated enough and clinical exposure is insufficiently frequent to maintain skills (see above).

Telemedicine Systems

Neonatal services are now partly centralised due to the appropriate development of neonatal networks and transport services, however there is still a significant amount of neonatal care which occurs outside of neonatal intensive care units and in local neonatal units and special care units. This means that these hospitals sometimes have to deal with unexpected seriously ill babies. There is the potential to implement telemedicine support for these services by investment in technology to allow support to all smaller hospitals by tertiary professionals and those working in transport services. This happens in some parts of Canada, the US and Australia to good effect. One example of an app to support this is being trialled in Scotland.

Action: Invest in development of telemedicine services for neonatal care

Translation services and other services to reduce inequalities

Significant health inequalities have been identified in maternity and neonatal services³⁰. Some of these exist because of the difficulties in access to high quality translation services which are person-centred, and this is a significant problem across health services.

Access to other services, information or research which could be used to build bridges between families from marginalised groups and maternity and neonatal teams and better access for clinicians to information/resources which helps them provide better care would be valuable. Examples might include improvements in monitoring devices for non-white babies.

Action: Investment in technologies to support high quality translation services which can be accessed 24 hours a day 7 days a week across the NHS.

Shift 3: Sickness to Prevention

Spotting illness earlier and tackling the causes of ill health could help people stay healthy and independent for longer, and take pressure off health and care services.

²⁹ Thematic Analysis of Neonatal Resuscitation in Term Neonatal Brain Injury and Early Death in England HSIB presentation at neonatal society. Nov 2024. Bowman et al.

³⁰ MBRRACE Perinatal Mortality Surveillance. UK Perinatal Deaths of Babies born in 2022. State of the Nation Report July 2024



Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Optimising Follow Up Care

Premature birth is known to be a causative factor for a range of long-term health challenges, including motor disorders, cognitive, social-emotional, mental health, behavioural, speech and language difficulties into school age and beyond³¹. Early intervention and early detection of deficit promotes better long-term outcomes and reduces the pressure on community services ³².

Guideline NG72³³ from the National Institute of Health and Care Excellence (NICE) sets out enhanced developmental support and surveillance which should be offered up until the age of two and up to the age of four in those most at risk³⁴.

Families whose babies most likely would have gone on to require multiple hospital admissions, or involvement from community services, are saved this added stress and in addition, the NHS is saved the additional cost³⁵. The Parent Infant Foundation in 2021 reported that "effective support for families in the earliest years brings savings to the public purse through reduced costs for public services and increased participation in the economy".

Currently this follow up is not routinely provided, particularly follow up at four. The House of Lords report 2024³⁶ highlighted "access to neurodevelopmental follow-up continues to be a postcode lottery, despite the publication of the NICE guideline" and reported that in 2022 "only 24% (39 of 162) of units achieved the NNAP developmental standard of 90% of babies receiving a two-year assessment".

This occurs because the guideline NG72 recommendation was introduced without specific funding and is beyond what most services have previously provided. It is also unclear whether the responsibility lie with neonatal or paediatric community services.

Action: It is vital that the NHS ensures funding and provision of follow up by a specialised multidisciplinary team to allow the full implementation of NG72.

Reducing Premature Birth:

Reducing premature birth through reductions in smoking, obesity and better understanding of mechanisms of preterm labour could have long term benefits. Supporting research in this area would have significant long-term benefits.

³¹ Altimer and Phillips 2016

³² Scottish Perinatal Annual Report Neonatal AHP Workforce Review 2022

³³ NICE, 'Developmental follow-up of children and young people born preterm': https://www.nice.org. uk/guidance/ng72

³⁴ NICE, 'Developmental follow-up of children and young people born preterm': https://www.nice.org. uk/guidance/ng72

³⁵ Scottish Perinatal Annual Report Neonatal AHP Workforce Review 2022

³⁶ Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024



A woman's individual risk of giving birth preterm is determined by a complex set of interrelated factors. Predicting and preventing preterm birth is therefore challenging. Screening and the targeting of treatment could be improved, but further research is required to understand the biological mechanisms underlying preterm labour, identify those women at greatest risk, and determine which interventions would most effectively support prevention³⁷. Optimising women's health prior to pregnancy is an important element of preterm birth prevention. This includes addressing social deprivation and potential risk factors such as smoking, drug use, obesity and mental health problems. An increased focus on this is likely to be necessary to achieve the kind of reduction in the preterm birth rate envisaged by the maternity safety ambition.

Optimising Perinatal Outcomes:

It has been successfully demonstrated that neonatal outcomes including survival and the risk of brain injury can be improved with optimal perinatal care including the provision of antenatal steroids, magnesium and delivery of the smallest babies in centres with the correct facilities. The optimal use of these interventions needs leadership and coordination. In areas where this has been done successfully reductions in mortality has been demonstrated and reductions in brain injury are likely³⁸.

PERIPrem (Perinatal Excellence to Reduce Injury in Premature Birth) is a care bundle that includes 11 interventions. These include many of the perinatal optimisation interventions recommended in the SBLCB, as well as the use of probiotics and prophylactic hydrocortisone. PERIPrem was developed by Health Innovation West of England, Health Innovation South West and the South West Neonatal Network. It was launched in April 2020 in those areas. PERIPrem was developed from the quality improvement theory of a previous project focussed on preventing cerebral palsy (PReCePT). It seeks to establish new ways of working, where clinicians from obstetrics, midwifery and neonatal join together to drive forward and revolutionise care for preterm babies.

Action: The NHS must take further action to ensure the consistent implementation of clinical guidance relating to preterm birth, particularly the perinatal optimisation interventions set out in the Saving Babies' Lives Care Bundle. Every region should have the resources to adopt the methodology of implementation programmes that have been shown to be effective and continue to strengthen maternal medicine and neonatal networks. In order to provide this in every region in the UK specific neonatal and maternity posts need to be funded which can help to deliver and coordinate these interventions.

Preventing RSV Infection

Babies discharged from neonatal units are frequently readmitted to hospital after their discharge and one of the commonest reasons for this is bronchiolitis (infection with respiratory syncytial virus (RSV)). Some benefit can be obtained in babies born preterm from regular (monthly) immunisations with Palivizumab, a specific immunoglobulin treatment. More recently the drug Nirsevimab has become available which can be given just once (rather than monthly) and helps significantly reduce the

³⁷ Preterm birth: reducing risks and improving lives. Preterm Birth Committee, House of Lords. Nov 2024

³⁸ The PERIPrem care bundle - Health Innovation West of England



incidence of infection and hospitalisation³⁹. Using this drug could help to prevent readmissions and hospitalisations and has the advantage of only being given once rather than monthly thus reducing hospital visits.

Ideas for change

We're inviting everyone to share their ideas on what needs to change across the health and care system. These could be:

- Ideas about how the NHS could change to deliver high quality care more effectively.
- Ideas about how other parts of the health and care system and other organisations in society could change to promote better health and/or improve the way health and care services work together.
- Ideas about how individuals and communities could do things differently in the future to improve people's health.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

• Quick to do, that is in the next year or so

- Establish Leads for Neonatal Outreach Care at Network/Regional Level and assess gaps in provision. Target funding for neonatal community outreach to the approximately 15%⁴⁰ of NICUs where there is no service at all, to begin development in line with new BAPM framework
- 2. Assess the requirements for full provision of TC in all neonatal services.
- 3. Analysis of the reasons for the gaps in medical workforce is required and a clear medical workforce plan for neonatal services needs to be developed.
- 4. Gap analysis for staffing of implementation of NICE NG72 (followup) Ensure funding is available to provide follow up for all babies at high risk by a specialist multi-disciplinary team.
- 5. Assess what is required to establish PeriPrem or similar project in every network.
- 6. Ensure that data systems implement the principle of data entered once and used for multiple purposes. This will avoid the time wasted, and the risk of errors, in duplicated data entry.
- 7. Review medical, and AHP staffing gaps and pharmacy and psychology in each network
- 8. Assess the reasons for gaps in AHP staffing. Ensure all 10 neonatal networks have the resources they need to recruit to all AHP psychology lead roles.
- 9. Assess the provision of network pharmacists' permanent appointments, quality roles, time for training, Investment in a substantive network-level pharmacy post for each ODN, to lead the improvement of medicines safety across all networks.

³⁹ Hammitt LL, Dagan R, Yuan Y, Baca Cots M, Bosheva M, Madhi SA, Muller WJ, Zar HJ, Brooks D, Grenham A, Wählby Hamrén U, Mankad VS, Ren P, Takas T, Abram ME, Leach A, Griffin MP, Villafana T; MELODY Study Group. Nirsevimab for Prevention of RSV in Healthy Late-Preterm and Term Infants. N Engl J Med. 2022 Mar 3;386(9):837-846.

⁴⁰ Neonatology. GIRFT Programme National Speciality Report April 2022



- 10. NHS England should publish the findings of its maternity and neonatal estates survey, setting out what proportion of neonatal units are currently able to provide sufficient accommodation for all families, as per the updated service specification for neonatal critical care and create a plan to remedy this.
- 11. Appoint a National Neonatal Safety Champion to drive improvements in safety, with a substantial focus on health inequalities.
- 12. Investment in technologies to support high quality translation services which can be accessed 24 hours a day 7 days a week across the NHS.
- 13. Start to develop electronic prescribing systems suitable for neonatal services.
- 14. Optimise FiCare in neonatal units:
 - Financial support for parents (food, parking, toilets, showers readily available)
 - Extension of Sophie's Legacy scheme https://www.sophieslegacy.co.uk/parentstobefed to provide free meals to parents of babies in neonatal care.
 - Update to the NHS Travel Support Scheme to include eligibility of neonatal parents to be able to claim travel expenses if they meet qualifying financial thresholds.
 - Development of fund through which neonatal units can purchase equipment to support parents to stay with their baby, e.g. recliner chairs and privacy screens.
 - Focus for next phase of Cultural Leadership programme specifically on the provision of culturally competent support for families to tackle inequalities in parent experience in neonatal units.
 - Develop guidance on joining-up post-natal maternity and neonatal care to support inpatient mums to be with their babies in neonatal care while also accessing the postnatal care and support they need.
- 15. Pilot implementation of telemed remote support for transport services and networks.

• In the middle, that is in the next 2 to 5 years

- 1. Establish commissioning pathways for neonatal outreach. Fully commission neonatal outreach care to ensure each baby/family who have experienced neonatal care has equitable access to a multidisciplinary outreach service.
- 2. The requirements for full provision of TC to the BAPM standard in all neonatal services should be assessed and adequately resourced to ensure provision of this service in every hospital providing neonatal care.
- 3. Every region should have the resources to adopt the methodology of implementation programmes (PeriPrem) and continue to strengthen maternal medicine and neonatal networks. Need funding of specific neonatal and maternity posts which can help to deliver and coordinate these interventions.
- 4. Funding and responsibility allocated for 4-year follow-up.
- 5. Provide a full NHS nursing bursary for student nurses and AHPs.
- 6. Fund nurse apprenticeships as a route into neonatal nursing.
- 7. Roll out a national electronic prescribing system to be used in all neonatal services



- 8. Provide protected time for training for all neonatal staff
- 9. Provide the time and resources to deliver simulation training particularly airway training for neonatal medical staff.
- 10. Establish a uniform career structure and progression for neonatal nurses.
- 11. Fund and recruit surgical specialist nurses to facilitate discharge of surgical babies
- 12. Investment in research that looks at any disparities of neonatal outcome and inequalities in the experiences of parents
- 13. Update to HBN building notes to ensure where builds are happening, they meet the requirements of families and support FICare.
- 14. Improved data around ethnicity and improved data flow within systems (between maternity, neonatal and paediatrics
- 15. Drug safety standardising drug concentrations, aseptic services making them up
- 16. Invest in development of telemedicine services for neonatal care

• Long term change, that will take more than 5 years

- 1. Establish a buildings programme for NICUs combined within the new hospital programme to enable cot expansion and adequate parent facilities for all neonatal units.
- 2. Recruit and train more AHPs, nurses and doctors and embed career pathways for AHPs.
- 3. Every parent being able to stay at their baby's side in neonatal care- requires capital investment
- 4. Ensure outreach services continue to maintain responsive service using technological advances to progress hospital at home services