GETTING IT RIGHT FIRST TIME

Neonatology

GIRFT Programme National Specialty Report

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GIRFT is part of an aligned set of programmes within NHS England and NHS Improvement

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Foreword from Professor Tim Briggs

I am delighted to recommend this Getting It Right First Time review of neonatology led by Eleri Adams, with nursing advisor Kelly Harvey and allied health professional advisor Michelle Sweeting.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The challenges – and the extraordinary response from everyone working in the NHS – add greater significance to GIRFT's recommendations, giving many of them a new sense of urgency.

Neonatal care continued throughout the pandemic but was still profoundly impacted, with many trusts reporting reduced parental and family access due to restricted visiting policies, some of which are still in place. Recommendations in this report can help the NHS to understand the role of parents as essential carers, not visitors, and to mitigate any potential neurodevelopmental consequences of necessary COVID-19 interventions such as face masks.

Eleri has applied the GIRFT approach to neonatal care. Getting it right at the very start of life obviously improves survival and outcomes for infants, but also has further benefits to outcomes and health in later life. Several landmark inquiries and reports have focused on neonatal and maternity care, and this GIRFT report is aligned with these reports and builds on them. This report highlights the significant progress made to date and adds detail on the implementation of existing recommendations, such as those set out in the Neonatal Critical Care Transformation Review.

The recommendations set out in this report are based on Eleri's deep-dive visits to trusts, alongside data and audits. Implementing the recommendations in this report will improve outcomes for infants and their families, while optimising the use of capacity and patient pathways. The experience of families is right at the heart of the report and its recommendations.

I am encouraged to hear that Eleri found so many examples of excellence in the trusts she visited, some of which are highlighted in this report as case studies. Like other GIRFT clinical leads, Eleri has been impressed by the commitment of all who work in neonatal care and encouraged by their engagement with the GIRFT programme and dedication to improving care.

This support is vital to the GIRFT programme, which can only succeed with the backing of clinicians, managers and everyone involved in delivering care.

My greatest hope is that this report will provide further impetus, encouragement and support to all those working in neonatal care to work shoulder to shoulder with parents, to improve experiences and outcomes for infants and families in the NHS.

Professor Tim Briggs *CBE*

GIRFT programme Chair and National Director of Clinical Improvement for the NHS

Professor Tim Briggs is consultant orthopaedic surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs. He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs. Professor Briggs is also National Director of Clinical Improvement for the NHS.

Foreword by Neil Marlow

Neonatal care has been the subject of important reports over the past 40 years. Almost all have identified shortfalls in the service provision, which have been identified clearly, but solutions have been hard to find. Will this report go the same way? For the first time I suspect not because I believe the NHS environment has shifted significantly over the past five years. There is now a great opportunity to 'get it right', although it isn't the first time! So, what has changed to make this more likely to succeed?

Starting with the publication of the Neonatal Service Specification by NHS England Specialised Commissioning there has been a steady and incremental series of developments to bind the NHS trust-based services into networks and to engage commissioners in the process. That this is happening at a time when the focus is on maternity transformation has meant that for the first time at a national level there is much better communication between maternity services – usually the province of midwives and obstetricians – and neonatal services – often considered part of paediatrics. In truth, they are one service and must move together to improve the service. Each of the two partners – mother and fetus – are equally important before and after the process of birth. Too often the fetus takes a second place before delivery and the mother (and family) after birth. As this report shows the family is as important in receiving and delivering care as the baby and services need to reflect this.

The second reason that this report should be more influential is its basis in the great work done by the NHS England Specialised Commissioning Clinical Reference Group, who developed an important national report for the managerial team and then produced a strong series of recommendations that have been backed up by funding and a system to monitor the implementation of changes, and thereby to hold trusts accountable for the funding targets, both workforce and infrastructure. This should ensure that the resources get to the place they are needed – the bedside.

It is against this backdrop that the GIRFT review was undertaken and, despite the Herculean challenge posed in its execution, it has successfully added more detail to the CRG and NHS England Specialised Commissioning action plan and made trusts much more aware of their comparative status in the greater scheme. We also now have Maternity and Neonatal Safety Champions on each NHS trust board, who can oversee the delivery of the necessary and clearly described changes, and a clear mandate to resource the network structures that bind the whole system together at a manageable and efficient population level.

There does need to be a mind shift for all to put the infant and family first – and I exhort all PPI representatives to maintain their pressure – but we have now clear and detailed direction. The GIRFT team and Dr Adams have done a tremendous job in compiling this project, visiting the trusts, and giving detailed pathways for delivery of a better future. It is now up to the trusts to ensure that it is implemented fully, including taking challenging decisions where it is clear that outcomes will be improved by doing so, and up to commissioners to use their influence to ensure it is delivered.

The earlier in life's journey we make our investment, the richer the rewards are likely to be. I commend this report – it is the right direction of travel, and all should support it.

Neil Marlow

Chair, NHS England and Neonatal Critical Care Transformation Review (2015-19)
Emeritus Professor of Neonatal Medicine, University College London

Statements of support

NHS England Clinical Reference Group

The GIRFT review of neonatology is a substantial report that supports the aspirations of the neonatal critical care transformation programme, which is to provide high quality neonatal services. The recommendations are far reaching and demonstrate the depth with which the review was undertaken. The review led by Eleri Adams rightly places patients and their families at the centre of the approach which was taken. Parents need to be recognised as essential carers and this is one of the GIRFT recommendations which is especially relevant considering the negative impact the Covid-19 pandemic has had on parental involvement in neonatal services.

Many areas of outstanding practice in clinical care are highlighted with vignettes used to bring some of these examples to life, however there is still significant variation in care across the country which leads to differences in outcomes, and this needs to be addressed. The report provides recommendations which address not only the key aspects of the Neonatal Critical Care Transformation Review (NCCR), but also highlights what could be achieved if recommendations for improvements in clinical care are taken forward; medication errors – reduced workload and reduced risk of errors, pulse oximetry screening – earlier detection of life threatening conditions, optimising breast feeding – reduced incidence of necrotising enterocolitis and optimising perinatal care – reduction in morbidity and mortality. The report provides a platform with which to begin to take things forward. It is really encouraging to note the level of engagement of nurses, clinicians, managers and commissioners during the GIRFT visits across the country; there is an appetite for improvement which bodes well for the future.

I would like to thank Dr Adams and the GIRFT team for an excellent report. I have no doubt that it will be welcomed by individuals involved in ensuring that neonatal services are safer, more efficient and cost effective and I fully support its findings and recommendations.

Ngozi Edi-Osagie
Chair, NHS England Clinical Reference Group for Neonatal Critical Care

British Association of Perinatal Medicine

The British Association of Perinatal Medicine warmly welcomes the GIRFT neonatal specialty report, commissioned in response to the NHS England Neonatal Critical Care Transformation Review (NCCR). The GIRFT team is to be congratulated on such a comprehensive assessment of neonatal services contained within this report and the additional GIRFT neonatal workforce report which complements it. Despite the challenges presented by the COVID-19 pandemic, the team has explored a wide range of aspects of clinical care and patient safety, both from the neonatal operational delivery network (ODN) and individual neonatal unit perspective.

Clear themes emerge from these data including the need to align neonatal care with both maternity and paediatric medical and surgical services as well as neonatal transport, the urgency of developing and retaining an expert multidisciplinary neonatal workforce, and the importance of retaining the family experience at the heart of all we do.

Neonatal services have undergone significant changes since the inception of networks in 2004 but the birth of ODNs has not always been easy. The GIRFT report contains examples of excellent practice while highlighting ongoing difficulties including a three-fold variation in funding for ODNs and significant short fall in transport services. It is pleasing to read that in a majority of areas relationships between the ODNs and the local maternity and neonatal systems, as well as fetal medicine networks, have improved in recent years. BAPM agrees strongly with the call to work more closely with colleagues in paediatric surgery in planning births of babies with known congenital anomalies.

No one who works in perinatal care will be surprised to read that there are neonatal capacity issues. Over 40% of our NICUs report a combined intensive/high dependency care cot occupancy of over 80% but almost one third of NICUs and LNUs are more than 10% below NCCR activity standards. As SCU admissions fall, there is an urgent need to review in conjunction with maternity services the location and designation of neonatal cots, as well as overall cot capacity.

Despite national guidance, the GIRFT report details significant variability in respiratory care, compliance with haematology guidelines and access to transcutaneous bilirubinometers as well as donor breast, to name only a few aspects of neonatal practice. There is additionally a concerning five-fold difference across networks in the proportion of babies born <27 weeks receiving chest compressions or adrenaline at birth. Acknowledging these differences must be the first step in ensuring equity of care for all born in the UK.

The importance of parental involvement in their baby's care cannot be overemphasised; the report contains some thought-provoking vignettes describing excellence in practice, but again highlights ongoing inadequacies in many aspects, including financial and psychological support for parents. BAPM applauds the call for universal provision of transitional care facilities as well as appropriate parent accommodation when a baby is resident in the neonatal unit.

This excellent GIRFT report should be essential reading for all involved in commissioning and practising perinatal care. If its practical and sensible recommendations are implemented across the UK, we shall undoubtedly see further improvements in outcomes for babies and their families.

Helen Mactier
President, British Association of Perinatal Medicine

Bliss

Bliss strongly supports the GIRFT Neonatology report, which provides an up-to-date assessment of neonatal services across England and sets out a comprehensive suite of recommendations to systematically improve neonatal care and, ultimately, outcomes for babies born premature or sick. Crucially, GIRFT highlights the central importance of supporting parents and families to be at the heart of their babies' care, and sets out a series of practical steps that must be taken to ensure that every baby is able to have their parents at their cot-side. The GIRFT report complements and builds on the foundation of the Neonatal Critical Care Transformation Review, and taken together they provide a significant opportunity to transform neonatal care in England over the next five years. It is vital that this opportunity is seized, and appropriate funding made available accordingly, in order to improve babies' lives over the long term.

Caroline Lee-Davey
Chief Executive, Bliss

The Neonatal and Paediatric Pharmacists Group

The Neonatal and Paediatric Pharmacists Group (NPPG) welcomes publication of this important neonatology report and associated workforce report, and supports the recommendations included within these reports.

Both reports highlight the important role of pharmacy in supporting care for neonatal patients and we encourage all organisations to use these reports to further develop and enhance pharmacy services in their neonatal units. The report recognises, alongside AHP services, the level of pharmacy support that is required to deliver a high quality service to neonatal units and regionally within the Neonatal Operational Delivery Networks (ODNs) and the extra work that needs to be undertaken to achieve this.

The reports also highlight the important safety issues relating to prescribing and administration of medicines to neonatal patients and how pharmacists can support development and introduction of electronic prescribing, use of standard infusion concentrations and the use of smart pumps to improve patient safety.

Nigel Gooding
Chair, Neonatal and Paediatric Pharmacist Group

Introduction

Improving morbidity and mortality for newborn infants has been a key national ambition since 2015, alongside reductions in maternal mortality and stillbirth. Much of the early work in this area targeted maternity and obstetric practices but the NHS England Neonatal Critical Care Transformation Review (NCCR), published in December 2019, focused on what could be done to improve neonatal outcomes. The GIRFT neonatology review was designed to complement this work, providing additional information in key areas highlighted by the NCCR, including capacity and patient pathways, family care and experiences, and the neonatal workforce (see the separate GIRFT Neonatology Workforce Report). In addition, the GIRFT review has explored aspects of clinical care and patient safety, with recommendations which, if implemented in all units, will lead to further improvements in outcomes for neonates and their families. Throughout this report the family experience has been at the heart of our approach, and we urge all readers to hold families in mind when reading all sections of this report, to ensure the impact of the neonatal journey is not lost.

GIRFT network visits started in February 2020, with trust visits ongoing at the time of writing. Thus, the review has primarily been conducted throughout the COVID-19 pandemic and we are grateful to all the teams involved for continuing work to improve neonatal care despite the many challenges they have faced during this time. Although COVID-19 caused minimal symptoms in most neonates, a few were affected by maternal ill health, and nearly all were profoundly affected by restrictive hospital visiting. Joint efforts from BAPM and the charity Bliss as well as campaigning by local clinical teams has improved understanding of the importance of parents as primary care givers, not visitors, and highlighted the potential impact that social distancing and wearing facemasks might have on neurodevelopment for these babies.

It was a privilege to undertake the GIRFT deep dive visits to neonatal operational delivery networks and trusts, to understand and share local and regional experiences. We gained much, personally, from doing so and hope that the actions and recommendations contained in this national report and the accompanying Neonatology Workforce Report, as well as those for individual trusts and networks, will prove useful to support ongoing improvements in neonatal care and outcomes, as well as family and staff experiences over the next five years.

Dr Eleri Adams

GIRFT Clinical Lead for Neonatology

Dr Adams is President Elect of the British Association of Perinatal Medicine (BAPM), and takes over as President in October 2022. She has been a consultant neonatologist at the Oxford University Hospitals NHS Foundation Trust since 2002 and was clinical director of the service for ten years. She has a keen interest in developing networked services, and led the Thames Valley Neonatal Network for 16 years. She is the vice-chair of the Neonatal Clinical Reference Group for NHS England where she led Quality Improvement and CQUIN development for several years. She is currently the pricing lead for the National Neonatal Transformation Review and also chairs the Neonatal Critical Care Expert Working Group for the National Casemix Office.

Kelly Harvey

GIRFT Nursing Advisor for Neonatology

Kelly has been a neonatal nurse since 2002 and has worked in a variety of clinical roles as well as education and management, latterly working as an Advanced Neonatal Nurse Practitioner. Her current role as a Quality Improvement Lead Nurse for the North West Neonatal Network allows her to fulfill her passion for ensuring standards of neonatal care for babies and families are of the highest standard. She is part of the BAPM Quality Collaborative where she was involved in the development of the quality improvement toolkits for preterm optimisation. She is an executive committee member of the National Neonatal Nursing Association through which she is keen to ensure the nursing voice is heard.

Michelle Sweeting

GIRFT Allied Health Professional Advisor for Neonatology

Michelle is a neonatal specialist Speech and Language Therapist (SLT) at Broomfield Hospital (Mid and South Essex NHS Foundation Trust) in Chelmsford where she has established a new service provision. Previously, Michelle was the Paediatric and Neonatal SLT lead at Barts Health NHS Trust. She has a range of experience of working in NICUs, LNUs and SCUs, over the past 18 years. Michelle has a keen interest in quality improvement and developing neonatal services which have allied health professionals embedded as part of multidisciplinary team.

Michelle is the deputy chair of the Royal College of Speech and Language Therapists Clinical Excellence Network and is an SLT representative for the Allied Health Professionals neonatal conference committee.

Executive summary

The GIRFT neonatology review follows NHS England's Neonatal Critical Care Transformation Review (NCCR), which published an action plan in December 2019 focused on aligning and investing in capacity, developing the expert neonatal workforce and improving the experience for families. The GIRFT review provides more granular detail on progress in these areas (see also GIRFT's Neonatology Workforce Report), as well as exploring new areas for improving clinical care and patient safety.

Strengthening Networks and Transport Services

Neonatal Operational Delivery Networks (ODNs) play a pivotal role in improving neonatal care and are highly effective organisations, having been in existence in England since 2004. We found that effective network functioning is hampered in some cases by lack of core funding and in most networks by difficulties making substantive appointments due to hosting organisations not wanting to hold financial risk when network funding is only secured from year to year. Commissioners and hosting organisations must establish a mechanism to allow for substantive appointments, and a national neonatal ODN service specification is needed, with funding arrangements futureproofed for the planned changes to funding models and the move to integrated care systems (ICSs).

Effective ODN functioning requires close working with Local Maternity and Neonatal Systems (LMNSs), and fetal medicine networks. These relationships were relatively poor in 2019 but there have been notable improvements in most but not all regions over the last 18 months. The footprints for these organisations should be aligned as much as possible with a similar collective ICS footprint and an overarching regional high risk perinatal group is recommended to streamline joint maternity and neonatal objectives. Recommendations are also given to strengthen relationships with other core stakeholders including parents, specialised commissioners, and paediatric clinical networks.

Neonatal transport service provision is critical to network function, ensuring both transfers for intensive care and repatriation to local units are carried out promptly when clinically appropriate. Benchmark data shows that a significant proportion of services are unable to comply with service specification response times and capacity benchmarks. In three out of ten networks, inadequate transport service provision was causing substantial delays to patient movement and clear and urgent action plans are needed to address these issues.

Improving Patient Pathways

A worrying but not unexpected finding is the severe capacity constraints in NICUs, with at least 48 additional cots required in these units to manage existing workload. At the same time, more than one third of both NICUs and LNUs have activity levels below NCCR recommended activity standards. Significant capital investment is needed alongside reconfiguration of services to implement optimal care pathways to improve patient outcomes. This requires strong leadership from specialist commissioning and significant capital funding. There is uncertainty regarding availability of funding in the NHS Long Term Plan for additional cot capacity and any critical gaps with no identified funding commitment will need escalation to specialised commissioning teams and ICSs for national review.

Care pathways that optimise the place of birth for infants at high risk of needing more complex care have a significant bearing on morbidity and mortality outcomes. Successful perinatal working has seen a significant increase in the proportion of extreme preterm infants born in the NICU and examples of how this was achieved are included in this report. There is room for further improvement in care pathways for both preterm infants and infants with congenital anomalies requiring early surgical or cardiac intervention. Additional data regarding transfers of infants from LNUs at 27-29 weeks' gestation is provided with recommendations to modify pathways for some low volume LNUs.

Reducing mother and baby separation remains a priority and reducing variation in the proportion of term and near term babies admitted to neonatal units (ATAIN programme), alongside development of transitional care and neonatal outreach, services will reduce length of stay and improve family experience. Potential financial opportunities from this approach are illustrated in the Financial Impact section of this report.

Optimising Clinical Outcomes for Preterm Infants

Half of all neonatal deaths occur in babies aged less than 28 weeks and therefore interventions should focus attention on this group of patients, particularly as there is ongoing significant variation in key morbidity and mortality outcome measures in this group across networks. There is much scope for improvement by focussing on perinatal and early postnatal management in the first few days of life including:

- Antenatal management: administration of magnesium sulphate, steroids, and antibiotics; birth in the NICU.
- Delivery room management: optimal cord clamping, maintaining normothermia and minimising use of invasive ventilation.
- Early neonatal management: early caffeine administration, use of synchronised volume-targeted ventilation, LISA for surfactant administration, avoidance of routine use of morphine during ventilatory management and early colostrum administration.

There has been progress in achieving some of these measures individually in the last few years but there is considerable room for progress. Deep dive visits suggest variable success with quality improvement work in this area, and excellent joint working across neonatology, obstetrics and maternity is required to be effective. All units are encouraged to review the examples of good practise included in this report, as well as the excellent resources available through BAPM, MatNeoSIP and PERIPrem. For improvements in breastmilk and breastfeeding, units are encouraged to seek funding to undertake the UNICEF Neonatal BFI accreditation scheme.

Reducing patient harm due to medication errors

Medication related events are one of the top three reasons for incident reporting in most neonatal units and information gathered during deep-dive visits suggests there is scope for improving safety. Several good practise examples of interventions used to reduce medication error in neonates are included in this report. Standardisation of drug and infusion practices at a national level is strongly recommended to reduce errors and following GIRFT discussion the RCPCH/NPPG Joint Medicine Committee has begun development of a national set of neonatal standard infusion concentrations for infants <2kg. Once completed, standardisation will increase the possibility of utilising ready-to-use concentrations of drugs and infusions for neonates, thus reducing nursing workload and risk of errors.

Pulse Oximetry Screening

Pulse oximetry screening (POS) has been shown to increase detection of critical congenital heart disease, and allow earlier detection and initiation of treatment for other potentially life-threatening conditions including sepsis, and pneumonia. More than half of neonatal units now perform universal POS for all infants but there is marked regional inequity. Several neonatal networks are working to support roll out of POS across their networks with an example included in this report. It is hoped that the national screening programme will reconsider inclusion of POS as part of the national screening programme in line with many other countries worldwide.

Improving Family Experiences

Parents and families play a vital role in supporting their baby whilst in neonatal care and should always be considered primary carers and not visitors. The covid-19 pandemic has particularly highlighted the need to advocate for the needs of families in neonatal units. Parent involvement in care is very important and is a focus for all neonatal units and is supported by use of the Bliss Baby Charter audit tool and UNICEF Neonatal BFI. Creation of network-wide parent passports to improve consistency for parents to continue care for their baby when they move between sites is an excellent idea and should be available in all networks.

Reducing parent-baby separation is a key focus, requiring development of transitional care facilities as well as appropriate parent accommodation for when a baby is resident in the neonatal unit. Our data shows there remains wide variation across units in the facilities available for families, particularly for siblings, and there is an urgent need to support improvements to counselling and bereavement facilities which were inadequate in 45% NICUs. Units can use the Bliss Baby Charter audit tool and UNICEF Neonatal BFI to support improvements.

This report once again highlights the significant financial burden on families with variation across trusts regarding support for parking, travel and meals. In many cases, families are partially or totally reliant on charitable funds for financial support. Benchmarking what is available to families across networks with a view to national alignment is recommended.

Last, but not least, psychological support for the whole family is inadequate in most units with a major gap in access and provision of mental health support for these families and this should be addressed with both local and national action required to achieve this.

Recommendations

Throughout this report, we make a series of recommendations and actions, based on the conclusions from our data analysis and deep-dive visits. All our recommendations and actions are presented in the tables below. Each lists the recommendation/action's owner and the proposed timeline for progress to be made on implementation. They are grouped based on the main sections of this report, and these sections provide greater detail on the supporting evidence and case for each recommendation.

Actions shaded in blue are key and a priority for implementation. Other actions are developmental.

Our recommendations for supporting the workforce are described in GIRFT's separate neonatology workforce report.

Recommendations to strengthen networks and improve patient pathways

Recommendation	Actions	Owners	Timescale from date of publication
1. Improve neonatal ODN effectiveness through development of a more consistent and equitable funding model, and strengthen relationships with key stakeholders.	**a** Develop an agreed requirement for national core network funding (relative to network activity) to ensure all networks have sufficient and equitable resource to be able to operate effectively across all areas of their remit. Arrangements must be futureproofed for changes to funding models and the move to ICSs. A national neonatal ODN service specification is needed which reflects these core funding requirements.	National & regional NHS specialised commissioning teams and Neonatal CRG	12 months
	b Put arrangements in place to allow for substantive appointments to network posts.	NHS regional specialised commissioning teams, network hosts	3 – 6 months
	c Strengthen commissioning relationships with neonatal ODNs. Strong commissioning leadership must be present to develop the business case for service change and subsequently support any reconfiguration / re-designation of services.	NHS regional specialised commissioning teams and neonatal ODNs	2 years
	d Ensure parents play an integral part in all aspects of network activity including representation on the network board.	Neonatal ODNs	6 – 12 months
	e Share ownership and joint working where neonatal ODN and LMS/LMNS work plans align. Planning guidance to LMS/LMNS for 2021/22 makes it clear that they must take responsibility for working with neonatal ODNs on implementing the findings of the NCCR.	Neonatal ODNs and LMSs/LMNSs	Immediate and Ongoing
	f Develop closer relationships with paediatric clinical networks, embedding paediatric sub-specialty input into antenatal and postnatal pathways within networks.	Neonatal ODNs, paediatric sub-speciality networks	1 – 2 years
	g Strengthen neonatal ODN relationships with LMSs/LMNSs and Fetal Medicine Networks (FMNs). The footprints for these organisations should be aligned as much as possible together with a similar collective ICS footprint. An overarching regional high risk perinatal group allows streamlining of joint maternity and neonatology objectives.	ICSs and regional specialised commissioning teams to lead	1 – 2 years

Recommendation	Actions	Owners	Timescale from date of publication
2. Regional neonatal transport services must meet national service specification standards and the requirements of neonatal ODNs.	**a** Ensure network risk registers include service specification response times and capacity benchmarks when they are consistently not met. Include current mitigations and an action plan. Urgent action is required where there is major disruption to patient flow.	Neonatal ODNs, Transport service providers	6 – 12 months
	b Confirm funding for transport services including ambulance provision, particularly where these services are integrated with NICUs. Capital funding for equipment should be included within funding allocations; charitable funding should not be the primary funding source.	Transport service providers, neonatal ODNs	1 – 2 years
	c Ensure consultant (tier 3) staff are always available 24/7 to perform transfers if clinically required. Where this is not currently possible, this issue should be on the trust and network risk register and include current mitigations and an action plan.	Transport service providers, neonatal ODNs, NHS regional specialised commissioning teams	1 – 2 years
	d Analyse the likely impact of changes to network pathways or configuration on transport service capacity and responsiveness.	Neonatal ODNs	Immediate and ongoing
3. Significant investment in additional cots is required to implement optimal care pathways as recommended in the Neonatal Critical Care Review (NCCR).	**a** Clarify the amount of capital funding available in the NHS Long Term Plan for additional cot capacity. Any critical gaps with no identified funding commitment will need to be escalated through regional specialised commissioning teams and ICSs for national review.	NIB, MTP, NHS National specialised commissioning team alongside regional specialised commissioning teams and ICSs	For immediate mitigation, 6 –12 months with definitive resourcing established in 2 – 5 years
	b Clarify how the capital funding model within NHS England is changing and how additional cots will be funded as the neonatal intensive care footprint is larger than the ICSs.	National specialised commissioning team and ICSs	3 – 6 months
	c Where neonatal ODNs and regional teams identify a clear need for increased capacity within a trust, there must be an action plan for implementation including current mitigations and escalation plans if difficulties are encountered.	Trusts, neonatal ODNs and NHS regional specialised commissioning teams, ICSs	6 – 12 months

Recommendation	Actions	Owners	Timescale from date of publication
4. Optimise antenatal and postnatal patient pathways and reduce unnecessary mother-baby separation.	**a** Ensure all network hospitals and cardiac and surgical service providers understand the importance of minimising mother baby separation and avoiding early postnatal transfer. Clarification of birthing hospital for high-risk surgical and cardiac conditions likely to require transfer in first 48 hours of life will help to address this.	Neonatal ODNs and transport services	3 – 6 months
	b Commit to joined up working between LMSs/LMNS, FMNs, neonatal ODNs, transport service providers and paediatric subspecialties to review all exceptions to the preterm designated antenatal and postnatal transfer pathways as well as for babies with congenital anomalies requiring urgent surgery. Feedback should be given to all clinicians across the relevant specialities regarding any learning outcomes including potential to improve antenatal diagnoses. For congenital anomalies, exception reporting and review is recommended for any infant requiring an intensive care transfer from a unit that is not the designated surgical birthing centre, to a surgical centre in the first 48 hours of life.	LMSs/LMNSs, FMNs, neonatal ODNs, paediatric sub-specialty ODNs and transport service providers	2 – 5 years
	c Consider, where capacity permits, adjusting gestational age for in-utero transfers in low volume LNUs (< 1,000 IC/HD per year) to under 29 weeks gestation and under 1,000g, to reduce known risks associated with transfer for this high-risk group pending any decisions regarding re-designation.	Neonatal ODNs, NHS Specialised Commissioning	Immediate and ongoing
	d Expedite plans for high-volume LNUs that do not meet BAPM staffing standards for Tier 1 and 2 rota separation to meet these standards. If it is likely to take some time, consideration should be given to temporarily adopting the adjusted thresholds suggested for low volume LNUs, network capacity permitting.	Trusts, neonatal ODNs	Immediate and ongoing
	e 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 AHP services. This may require network and commissioning involvement to develop services across the footprint of the network.	Trusts, neonatal ODNs and NHS regional specialised commissioning teams	2 – 5 years
	f Consider maternity unit size, and projected changes to maternity activity alongside socioeconomic factors when evaluating whether an LNU or a SCU is more appropriate for the local population.	Neonatal ODNs and LMSs/LMNSs	Immediate and ongoing
	g Continue to work on strategies to reduce term admissions into neonatal units, particularly units with above average term admissions, including development of transitional care in line with BAPM Framework, and adherence to existing guidance (ATAIN) and CNST requirements.	LMSs/LMNSs and Trusts	Immediate action

Recommendations to improve clinical aspects of neonatal care

Recommendation	Actions	Owners	Timescale from date of publication
5. Improve attainment of key optimal start metrics for preterm infants. These include the following core items: • born in NICU; • antenatal steroids; • antenatal MgSO4; • antenatal antibiotics; • Optimal cord management; • normothermia on admission to NICU; and • colostrum within 24 hours.	**a** Review available benchmarking data to develop formal annualised QI plans at trust and neonatal ODN level to support improvements in optimal start interventions (and other interventions where planned). Trust-level plans should be submitted to their network.	Neonatal ODNs and trusts	12 months
	b Utilise national QI resources e.g. BAPM/ MatNeoSIP to improve optimal start metrics. Sharing of resources, data analyst support and shared practice will reduce the burden on individual units and provide a supportive structure for improvement.	Neonatal ODNs, trusts, AHSNs and MatNeoSIP	Immediate and ongoing
	c Increase perinatal working, with close maternity and neonatal collaboration at network, transport and unit level to improve optimal start metrics.	Neonatal ODNs, trusts and LMSs/LMNSs	Immediate and ongoing
	d Establish a joint review by LMSs/LMNSs and neonatal ODNs of preterm babies <27 weeks who received higher levels of resuscitation (cardiac compressions and/or adrenaline) to review outcomes and determine any common themes or actions to improve perinatal care.	Neonatal ODNs and LMSs/LMNSs	1 – 2 years
6. Maintain skills and confidence for all neonatal clinical staff, particularly those working in LNUs and SCUs, managing emergency situations which occur infrequently outside the NICU setting.	**a** Provide education and simulation training, at least annually but ideally bi-annually, for the entire workforce to ensure confidence and skills are maintained in early preterm stabilisation and other emergency scenarios requiring neonatal emergency procedures, such as exchange transfusion and chest drain placement.	Neonatal ODNs, trusts and LMSs/LMNSs	12 months
	b Offer supernumerary time for LNU/SCU staff to spend in NICUs to increase exposure to intensive care.	Trusts	1 – 2 years
	c Look at ways to improve rapid access to expert clinical advice during stabilisation and intensive care support, including use of new technologies such as telemedicine.	Neonatal ODNs, trusts, neonatal transport services	2 – 5 years
7. Implement NICE guideline NG124 specialist neonatal respiratory care for babies born preterm.	**a** Develop local guidance for preterm infant respiratory support in delivery suites to minimise use of mechanical ventilation.	Neonatal ODNs and trusts	6 – 12 months
	b Provide guidance and training in use of minimally invasive techniques for administering surfactant.	Neonatal ODNs and trusts	12 months
	c Provide guidance and training on use of synchronised volume-targeted ventilation.	Neonatal ODNs and trusts	24 months
	d Support units to develop business cases for purchasing ventilators that are able to deliver synchronised volume-targeted ventilation. Consideration should be given to purchasing the same ventilator across LNUs and SCUs within a network to simplify training and potentially reduce cost (see also recommendation 21).	Neonatal ODNs and trusts	1 – 2 years

Recommendation	Actions	Owners	Timescale from date of publication
8. Improve early access to breast milk and sustaining numbers of preterm babies receiving breastmilk during their entire stay in the neonatal unit.	**a** Use the BAPM Breastmilk Toolkit to improve the numbers of preterm babies receiving breastmilk during their entire stay in the neonatal unit.	Neonatal ODNs, trusts	6 – 12 months
	b UNICEF Neonatal BFI accreditation is strongly recommended, and funding sources should be sought at local and national level. Funding is on offer for maternity services to support UNICEF Maternity BFI through the NHS Long Term Plan and there is a strong case for central funding for UNICEF Neonatal BFI accreditation.	NHSE National specialised commissioning team, Maternity Transformation Programme, LMSs/LMNSs, neonatal ODNs and trusts	1 – 3 years
	c Improve network guidance to support equal access to donor breastmilk across the region for the most high-risk infants.	Neonatal ODNs	6 – 12 months
9. Reduce unnecessary transfusion of blood components, donor exposure and adverse outcomes of transfusion in neonates.	**a** Locally adapt and implement network-wide guidance on transfusion for neonates based on national best-practice guidelines.	Neonatal ODNs	12 months
	b Provide appropriate transfusion training to all staff prescribing and administering blood components for neonates, including reviewing key educational messages from paediatric reports in the national haemovigilance system (SHOT).	Trusts	12 months
	c Audit blood testing practices with the aim to eliminate unnecessary tests and minimise blood volumes taken.	Trusts	1 – 2 years
	d Conduct further research trials to improve safe and effective transfusion practise in neonates and neonatal units should be encouraged to participate in approved trials.	Clinical academic neonatal practitioners / haematologists/ Trusts	2 – 5 years
10. Improve the pathway for babies presenting with bilious vomiting to reduce unnecessary transfers and reduce delays in access to surgical review and upper GI contrast study.	**a** Develop a National Framework for Practice for babies presenting with bilious vomiting with involvement of a multidisciplinary working group.	BAPM, BAPS, NTG, BSPR, RCR	1 – 2 years
	b Form a cross-party working group, including service user representation, to develop standards for radiology / radiography services needed in NICUs, LNUs and SCUs.	BAPM, BSPR, RCR, SCoR	1 – 2 years
	c Review pathways for babies with bilious vomiting and work with surgical NICUs, transport services and all service providers to improve the pathway, including minimising mother-baby separation. Consideration should be given to developing "drive-through" pathways for well infants.	Neonatal ODNs, surgical NICUs, patient transport services, paediatric radiology and radiography	1 – 3 years

Recommendations to strengthen clinical governance and safety, and reduce litigation

Recommendation	Actions	Owners	Timescale from date of publication
11. Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**a** Implement a clear governance and communications structure from neonatal ODNs to specialised commissioning.	Neonatal ODNs, regional specialised commissioning teams	6 – 12 months
	b Review neonatal risk registers quarterly at both network and trust level. There should be clearly outlined processes for escalation of risk within the trust, from trust to network and from network to region.	Neonatal ODNs, regional specialised commissioning teams, trusts	6 – 12 months
	c Coordinate an approach to maternity and neonatal governance at both local and regional level. Whilst recognising that particular issues may require more in depth focus at specialty level, there must be appropriate overarching structures for both governance and mortality review.	LMSs/LMNSs, neonatal ODNs, trusts, trust maternity and neonatal safety champions	12 – 18 months
	d Standardise the neonatal death review process within the network. All deaths should be reviewed at network level and include LMS/maternity representation. Networks should have oversight of local trust mortality review and PMRT outputs and the networks should be involved in neonatal Child Death Overview Panels to provide a more robust mortality review framework.	Trusts, neonatal ODNs, LMS/LMNS/ CDOP panels	12 months
12. Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**a** Develop a national set of neonatal standard infusion concentrations to reduce the risk of errors occurring when babies are transferred between units; increase viability of commercial production of the required medication strengths; and improve consistency for education and training.	National Patient Safety Programme, RCPCH Joint Medicine Committee	1 – 2 years
	b Increase the use of ready-to-use standardised concentrations of drugs and infusions, prepared in pharmacy aseptic services or by external suppliers, and reduce local drug preparation in neonatal units.	Neonatal ODNs, trusts, regional perinatal safety groups, NPPG, NHS pharmacy aseptic services	2 – 5 years
	c Adjust, where applicable, trust or network-developed drug calculators to ensure they are updated against MHRA advice and can be used across networks. Existing drug calculators should not be removed until a safer sustainable alternative is in place.	Neonatal ODNs and trusts	6 – 12 months
	d Ensure standardised parenteral nutrition (PN) bags are available for both initial and maintenance PN in all NICUs and LNUs and consider network-wide standardisation (see also our recommendations about procurement). PN bags should comply with national nutritional recommendations for neonates as well as safety standards, including mechanisms to avoid accidental lipid over-infusion.[1]	Trust pharmacy leads with input from neonatal ODN.	12 months
	e Ensure all neonatal units have access to a pharmacist with competence to provide advice for prescribing and monitoring of PN to complex patients.	Trusts, neonatal pharmacists	12 months

[1] *https://www.england.nhs.uk/publication/patient-safety-alert-infusing-total-parenteral-nutrition-too-rapidly-in-babies/*

Recommendation	Actions	Owners	Timescale from date of publication
12. (continued) Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**f** Enable staff in all units to regularly practise preparing drugs and infusions commonly used in neonatal intensive care.	Trusts, neonatal ODNs	Immediate and ongoing
	g Prioritise rolling out suitable electronic prescribing systems for neonatal care. These require a high level of involvement from neonatology teams and neonatal pharmacists to ensure the design is fit for purpose. Where the existing trust prescribing system is not deemed safe for neonatal use, it must be suitably adapted, or an alternative product used.	Trusts, neonatal pharmacists	2 years
	h Implement smart pump technology in conjunction with advice and recommendations found in HSIB smart pump report[94] and audit the impact on medication errors in neonates.	Trust and network neonatal pharmacy leads	1 – 2 years
13. Improve prompt recognition, diagnosis and treatment of conditions commonly screened for or assessed in the neonatal period, which are more likely to result in significant clinical harm.	**a** Review the evidence for pulse oximetry screening and work together to support role out of pulse oximetry screening (POS) across all networks.	Neonatal ODNs, LMSs/LMNSs	1 – 2 years
	b Reconsider inclusion of pulse oximetry screening as part of the national screening programme given the increasing number of neonatal units already undertaking universal screening that results in significant regional inequity in identification.	UK NSC	12 months
	c Ensure all hospital and community services have access to transcutaneous bilirubinometry (TcB) in line with NICE guidance.	Trusts, maternity and neonatal service providers	12 months
	d Implement clearly agreed antenatal and postnatal pathways for managing infants at high risk of needing an exchange transfusion in the neonatal period. Delivery should be planned at a site where the neonatal unit has appropriate staffing and expertise on site ***at all times***.	Neonatal ODNs and LMSs/LMNSs, FMNs	6 months
	e Training for staff performing newborn infant checks must include information regarding anorectal anomalies and the fact they may be more likely to be missed when meconium is passed through a fistula.	Trusts, neonatal ODNs, LMSs/LMNSs	Immediate and ongoing
	f Raise awareness of signs consistent with spinal cord anomalies in the newborn period and establish network-wide protocols for initial management and referral pathways. This should be done jointly between paediatric neurosurgical services/networks and neonatal ODNs as part of a wider collaboration between the two networks with regards to neurosurgical pathways (see GIRFT's Paediatric Neurosurgery report).	Neonatal ODNs, paediatric neurosurgical services / networks	6 – 12 months
	g Review NICE guideline: Neonatal Infection (NG195), and HSIB's national learning reports on group B streptococcus (July 2020) and neonatal collapse (Aug 2020) recommendations and amend local guidelines and education material accordingly.	Neonatal and maternity units	6 – 12 months
	h Optimise evidence-based infection reduction strategies and submit accurate verified infection data to NNAP.	Neonatal units, neonatal ODNs	12 months and ongoing

Recommendation	Actions	Owners	Timescale from date of publication
14. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity.	Trusts	Immediate and ongoing
	b Clinicians and trust management to discuss with the legal department or claims handler, the claims submitted to NHS Resolution in the data set, to confirm correct coding to neonatology as claims for neonates can occur in neonatology, paediatrics (including paediatric subspecialties), paediatric intensive care or maternity, all claims for infants <28 days old at the time of the incident, should be reviewed by the respective teams to ensure accurate assignment of the claim to the correct team. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk Note: Coding of claims to neonatology commenced in April 2020.	Trusts	Following completion of above
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trusts panel firm should be able to provide support.	Trusts	Following completion of above
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SI) and where a claim has not already been reviewed as SI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with networks and all front-line clinical staff in a structured format at departmental / directorate meetings (including multidisciplinary team meetings, morbidity and mortality meetings and regional service meetings where appropriate).	Trusts	Following completion of above
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional hubs to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	Trusts	For continual action throughout GIRFT programme

Recommendations for improving the support given to families

Recommendation	Actions	Owners	Timescale from date of publication
15. Facilities for families should allow parents to remain with their baby at all times if their circumstances permit.	**a** Increase the range of services provided within transitional care to reduce mother-baby separation, and where possible to provide more flexibility for partners to also be caregivers.	Trusts, neonatal ODNs, maternity services, network care coordinators	2 – 5 years
	b Urgently address inadequate or poor-quality counselling and bereavement facilities. Seek input from families to determine needs.	Trusts	6 – 12 months
	c Work with families to understand the gap in provision of facilities and address inequities, in line with established guidance.[2] Where new units are planned, parent facilities should receive the same priority as clinical space.	Trusts, neonatal ODNs, network care coordinators	2 – 3 years
	d Research and determine what tailored support can be made available for siblings.	Trusts	2 – 3 years
16. There must be consistent and equitable financial support for parent travel, subsistence and accommodation requirements.	**a** Benchmark current financial support available to families including parking, accommodation, food and drink and travel costs, making best use of available evidence.	Neonatal ODNs and trusts, with input from Bliss	2 years
	b Share network findings with the Neonatal CRG and BAPM to support alignment nationally.	Neonatal ODNs, neonatal CRG, BAPM, with input from Bliss	2 years
	c Provide consistent and equitable financial support to families across the network. Ensure families are aware of their statutory entitlements and how to claim.	Trusts, neonatal ODNs, local charities	2 – 5 years
	d Provide free, or discounted, parking for all parents of neonatal inpatients for the duration of their stay.	Trusts,	2 – 3 years
17. Family Integrated Care must be fully embedded in all neonatal services and networks should ensure family training and involvement in care are the same across different providers in the baby's journey.	**a** Consider a unified approach across the network to improve the journey for families transferred between providers. This should include development of parent passports to provide consistency for parents to continue care for their baby when they move between sites.	Regional neonatal ODNs, network care coordinators	2 – 18 months
	b Parents must be considered as essential carers not visitors. Nationally, continue to champion the needs of families in neonatal units during world events that potentially restrict patient access (e.g. the COVID-19 pandemic) in order to reduce the potential neurodevelopmental consequences of these restrictions.	Neonatal CRG, Bliss, NNA and BAPM	Immediate and ongoing
	c Ensure every provider of neonatal care has a clear action plan for ongoing development of partnership care with families using QI tools such as the Bliss Baby Charter, UNICEF Neonatal BFI (see action 8b) and BAPM Framework for Family Integrated care. This work should have senior nursing and AHP leadership involvement alongside the family voice.	Trusts, neonatal ODNs, network care coordinators and network AHPs	6 – 12 months

[2] *https://www.gov.uk/government/publications/guidance-on-the-planning-and-design-of-neonatal-units*

Recommendation	Actions	Owners	Timescale from date of publication
18. Psychological support services should be accessible to all families during their stay in the neonatal unit, with seamless links to community perinatal mental health services as and when they are appropriate for an individual family.	**a** Benchmark the level of psychological support required against the current standard (BPS Perinatal Services 2016) and the anticipated neonatal standards due to be set by the British Psychological Society (see workforce report recommendation 2b).	Trusts, supported by network psychology leads	1 – 2 years
	b Actively address the psychological needs for the whole family throughout the neonatal unit journey and post discharge. There is a major gap in access and provision of Perinatal Mental Health support for these families and this must be addressed. This needs to be taken forward both locally and nationally.	NIB, national & regional specialised commissioning teams, PNMH/neonatal ODNs, trusts	2 years
	c Encourage local and regional links to peer support groups and charities to support improved psychological support.	Neonatal ODNs, network psychology leads, trusts, local charities	6 – 12 months
	d Raise awareness of the psychological impact of the neonatal experience on families among all professionals but particularly those working in the community who have little exposure to neonatal care.	Neonatal ODNs, network psychology leads, network care coordinators, network AHPs	12 – 24 months
19. Robust mechanisms must be in place to include a wide range of parent voices with diverse backgrounds and neonatal experiences in service development and quality improvement across networks and trusts.	**a** Make available Neonatal Parent Advisory Groups/ Neonatal Voices Partnerships or equivalent across all neonatal networks. Links made to MVPs and other parent voice provisions within the local area provide a wide-reaching voice to a diverse population.	Neonatal ODNs, LMSs/LMNSs, MVPs and trusts, care coordinators	6 – 12 months
	b Ensure each local provider of neonatal care has a robust mechanism for parent feedback. This may be developed at a network level.	Neonatal ODNs, network psychology leads and/or care coordinators, trusts	6 – 12 months
	c Ensure there is a mechanism for parents to show how their feedback has been actioned and how this has affected change. This should be updated at least biannually.	Trusts, care coordinators	6 – 12 months

Recommendations to improve data capture and reporting

Recommendation	Actions	Owners	Timescale from date of publication
20. Ensure seamless and accurate data flow of mandatory datasets for network pathways and flows, national and regional audit, benchmarking, research, pricing and national cost collections (NCC).	**a** Provide sufficient support locally (clinical and administration time) to ensure accurate data collection for the neonatal critical care minimum data set (NCCMDS), NNAP, and NMPA. Include appropriate clinical job planning to support data checking and submission.	Trusts	Immediate and ongoing
	b Verify data accuracy and completeness in the annual NNAP data returns.	Trusts	Immediate and ongoing
	c Ensure accurate activity submission to NCC and SUS, and accurate cost submissions to NCC, with use of cost weightings included in National Cost Collection guidance. There should be evidence of clinician involvement in this process.	Trusts	Immediate and ongoing
	d Ensure, as EPR systems develop, that duplicate data entry is avoided with seamless dataflows for payment, costing, audit and research	Trusts, NHS Digital, NHSX	2 – 5 years
	e Explore development of a national Neonatal Services Monthly Statistics Dashboard along similar lines to the Maternity Services Monthly Statistics Dashboard.	Neonatal CRG, NHS Digital	12 months
	f Provide quarterly dashboards for key NNAP and maternity dashboard measures to support improvements in data quality, local benchmarking and improvements in NNAP measures.	Neonatal ODNs	6 - 12 months
	g Engage with trust level Patient Level Information and Costing System (PLICS) collection for neonatal critical care in line with national timetables.	Trusts	2 years
	h Agree an amendment to the data flow for SUS to allow linkage of each neonatal HRG bed-day to the location of care to improve accuracy of the data flow to SUS.	National Casemix Office, NCC EWG	12 months

Recommendations for standardising procurement models to support neonatal care

Recommendation	Actions	Owners	Timescale from date of publication
21. Neonatal ODNs to work with local providers and agree procurement models, so consumables and devices used more infrequently are consistent across a network, the GIRFT 3-point strategy should be used to support this process.	**a** Agree a procurement framework across the Neonatal ODN, with a particular focus on parenteral nutrition, neonatal ventilators and equipment for therapeutic hypothermia.	Trusts with input from Neonatal ODNs, NHSX	2 – 5 years
	b Use sources of procurement data, such as SCS and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	GIRFT	Ongoing
	c Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	GIRFT	Ongoing
	d Use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Trusts, neonatal ODNs, GIRFT	Ongoing

About Neonatology

What is neonatology?

Neonatology is a subspecialty of paediatrics which provides care for sick babies and their families around the time of birth and for the first weeks of life. Services include antenatal counselling where a fetal anomaly has been detected or premature birth is anticipated; support for new-born babies receiving resuscitation at delivery and during the early postnatal period; and critical care services for sick preterm and term neonates and their families.

In addition to inpatient care, neonatology services often provide community outreach support for more vulnerable babies following discharge from hospital. In some areas, these services are becoming more developed and can include support for babies requiring home tube-feeding, home oxygen therapy, phototherapy for jaundice, and/or intravenous antibiotics. Neonatology services also provide outpatient follow-up for babies with ongoing medical problems post hospital discharge, and neuro-developmental surveillance for infants at high risk of neurological sequelae.

Neonatology services work very closely with maternity services to ensure that babies at high risk of being born very prematurely or needing intensive care are born in the right place, to prevent early postnatal transfer where possible. There is also close collaborative working in postnatal and transitional care areas, particularly with regards to monitoring and management of babies who are at higher risk of becoming unwell, and in the delivery of transitional care services.

There is also a close working relationship with several paediatric subspecialities, most commonly paediatric surgery, cardiology, neurosurgery, respiratory, ophthalmology, radiology, community paediatrics and paediatric critical care. Where babies require ongoing care beyond the neonatal period (first 28 days of life, or for infants who are born prematurely, beyond 44 weeks' postmenstrual age) care is usually transferred to the appropriate paediatric service at a suitable point in the baby's journey.

Care levels: specialist neonatal critical care HRGs

There are five levels of neonatal critical care activity calculated daily using the neonatal critical care minimum dataset (NCCMDS), which records the activities and procedures that occur over each 24-hour period and uses these to generate a specialist neonatal Healthcare Resource Group (HRG) code.

Amendments to the NCCMDS and changes to the algorithms for generating HRGs occurred in 2016. HRG codes calculated using the new algorithms are commonly referred to as 2016 HRGs and all data in this report (including data preceding 2016) is calculated using the new algorithms. The specialist Neonatal Critical Care HRGs are shown below.

Table 1: Specialist neonatal critical care HRGs

HRG code	HRG name	Examples of care given
XA01Z	Neonatal Critical Care, Intensive Care	Mechanical ventilation, therapeutic hypothermia
XA02Z	Neonatal Critical Care, High Dependency	Parenteral nutrition, non-invasive respiratory support e.g. CPAP
XA03Z	Neonatal Critical Care, Special Care, without External Carer	Low flow oxygen therapy, care of stoma
XA04Z	Neonatal Critical Care, Special Care, with External Carer	Tube feeding, intravenous antibiotics
XA05Z	Neonatal Critical Care, Neonatology Supportive Care	Phototherapy

Intensive care (IC) and high dependency care (HD) takes place within neonatal units, whereas special care (SC) can take place within neonatal units or, increasingly, in other settings where a mother or the whole family can be resident with their baby, such as neonatal transitional care (TC). Parents and families are key partners in providing care for their baby and their input as primary carers, not visitors, is vital to provide the best outcomes for these babies.

Organisation of neonatal care

Neonatal unit designations

Hospitals provide three different types of neonatal service for their local population:

- **Neonatal Intensive Care Units** (NICUs) provide IC for the smallest and sickest babies across the whole region, in addition to HD, SC and TC for their local population.
- **Local Neonatal Units** (LNUs) provide short-term IC (1-2 days); and HD/SC and TC services for their local populations.
- **Special Care Units** (SCUs) provide SC/TC for their local population.

All types of neonatal service provide support to maternity wards for babies with additional needs. Some services have separate transitional care wards for these babies, whilst other services provide support within the postnatal ward setting.

There are 156 neonatal units in England; 43 NICUs; 75 LNUs and 38 SCUs. The different types of neonatal services have varying medical and nurse[3] staffing requirements, and standards for these are set by British Association of Perinatal Medicine (BAPM).

Neonatal Operational Delivery Networks (ODNs)

Neonatal networks play an essential role in coordinating neonatal care across regions. Each network consists of several NICUs, LNUs and SCUs, and a specialist neonatal transport service, supported by a network management team. They all work in a coordinated fashion to provide equitable access to intensive care services and deliver high-quality care for all patients as close to home as possible.

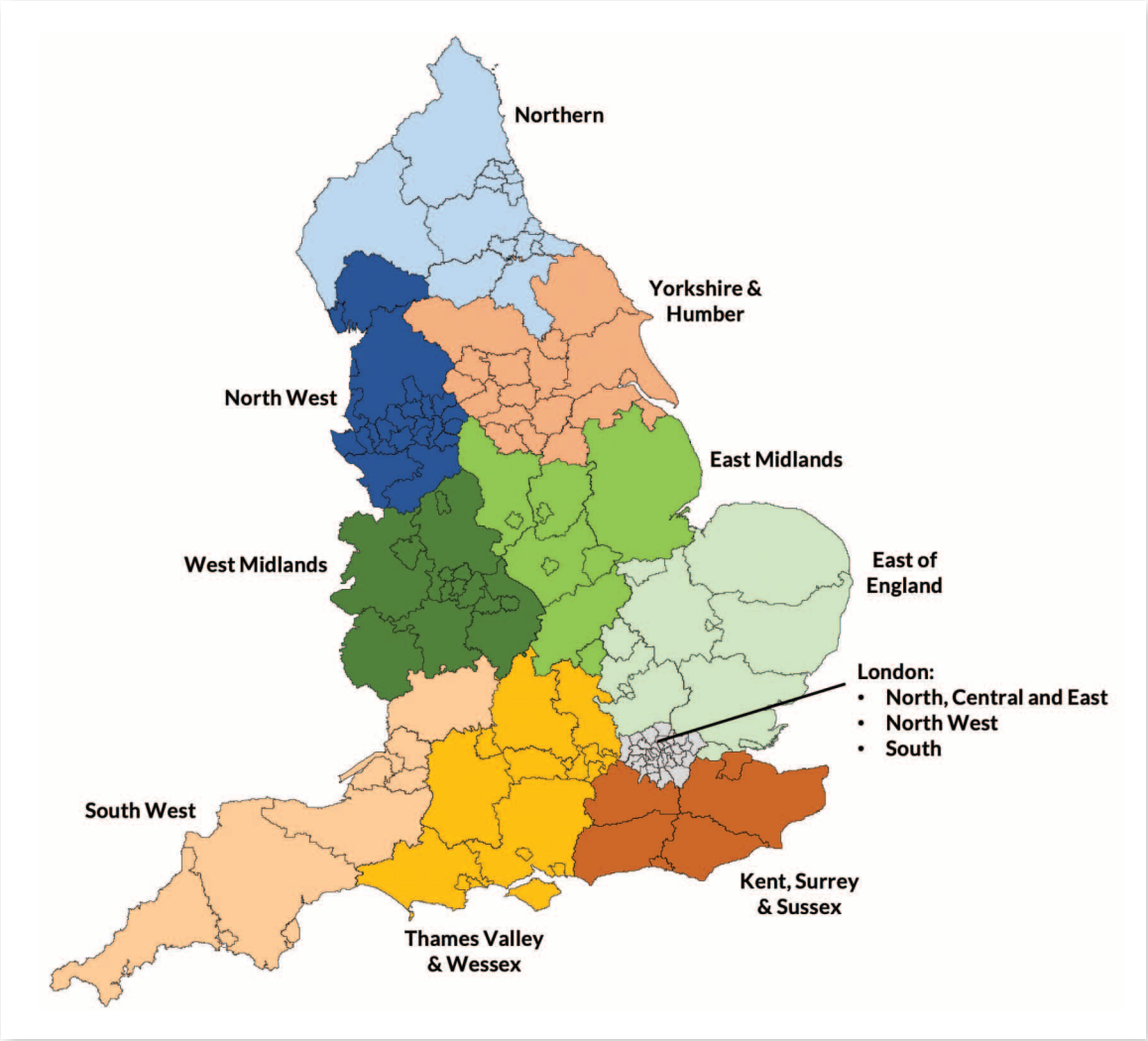
Networked organisation of neonatal care was formalised in England and Wales in 2004 in recognition of emerging evidence that outcomes were improved for the smallest and sickest infants if care was centralised to larger intensive care units.[4] These organisations have evolved and matured and there are now ten neonatal operational delivery networks (ODNs) commissioned by NHS England Specialised Commissioning. Their mandate is to ensure appropriate and equitable access to specialist resources and improve neonatal outcomes and patient experience.[5]

[3] *Throughout this report, when we use the term "nurse" we are generally referring to registered nurses*

[4] *Department of Health (2003) Neonatal Intensive Care Review: Strategy for Improvement*

[5] *NHS England (2013) Developing Operational Delivery Networks: The Way Forward*

Figure 1: Configuration and structure of neonatal operational delivery networks



Neonatal ODN	Births	Network Admissions	Clinical Neonatal Networks	NICUs	LNUs	SCUs
London	125,279	11,016	3	8	14	4
North West	77,036	7,180	3	7	13	1
East of England	65,458	6,396	4	3	10	4
West Midlands	64,442	6,100	2	5	5	4
Yorks & Humber	62,625	5,155	4	4	10	4
TV & Wessex	52,984	4,515	2	3	9	2
Kent, Surrey & Sussex	48,804	3,993	3	4	3	6
South West	44,611	3,962	1	3	6	3
East Midlands	43,743	4,394	2	3	5	3
Northern	30,598	2,489	1	3	0	7
Total	**615,580**	**55,200**	**25**	**43**	**75**	**38**

Note: activity data relates to FY2018/19

Source: BadgerNet/GIRFT Network & Trust Clinical Services Questionnaires

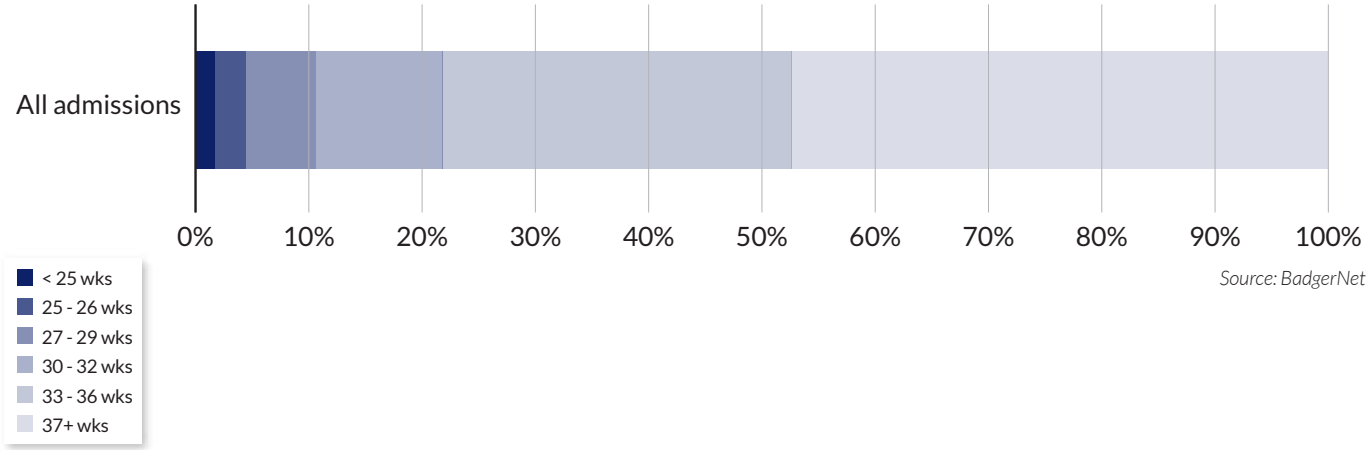
Activity trends

GIRFT key findings:

- 9% of babies born in 2018/19 were admitted to neonatal units.
- 47% of all babies admitted are term infants.
- There has been a 6% fall in total neonatal critical care activity (IC/HD/SC) since 2015.
- There has been a sharper fall in special care activity (9%) compared with birth rates (6%) since 2015. This is likely to reflect work done by trusts to reduce mother-baby separation through the ATAIN programme.

More than 55,000 babies were admitted to neonatal units in 2018/19, comprising more than 9% of live births. Nearly half (47%) of all babies admitted are term infants (born at gestational age 37 weeks or more) and 4% of babies admitted are less than 27 weeks' gestation, which are the group requiring initial care in a NICU (**Figure 2**).

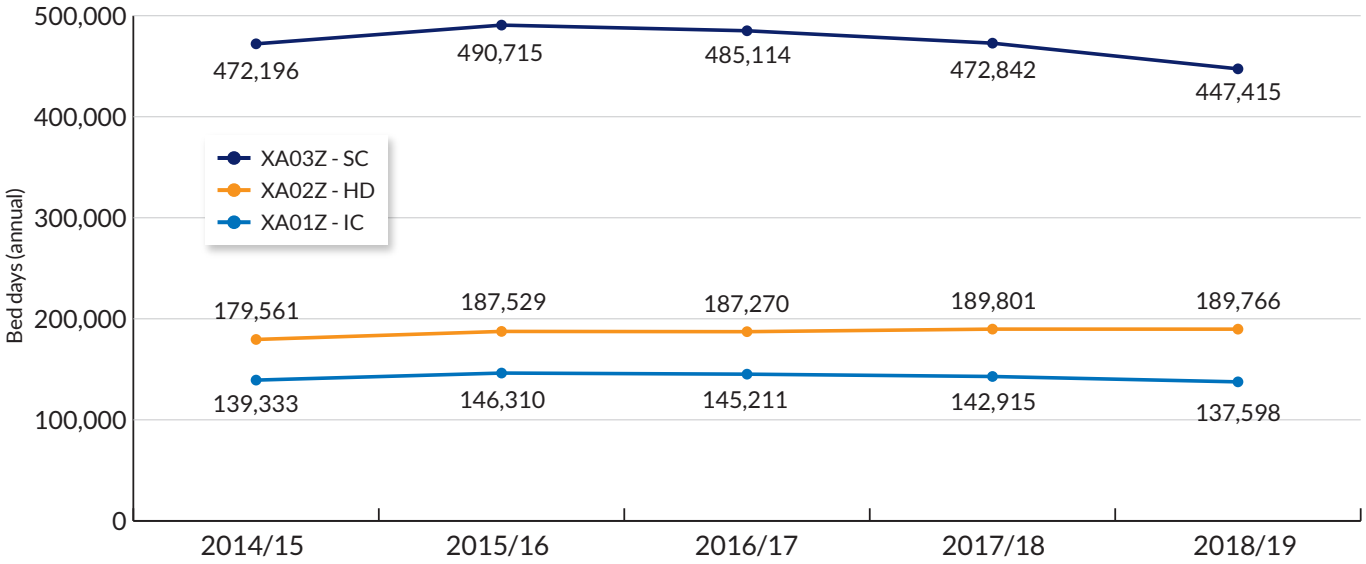
Figure 2: Proportion of babies admitted to neonatal units at different gestational ages



Source: BadgerNet

There has been a 6% fall in total critical care activity since 2015, with a 9% reduction in special care activity, a 6% reduction in intensive care activity and a small rise (1.2%) in high dependency activity (**Figure 3**). Nearly 775,000 bed days of critical care (HRG XA01Z-03Z) took place in neonatal units with 52% of activity in NICUs, 39% in LNUs, and 9% in SCUs.

Figure 3: Trends in critical care activity 2015-19 (total bed days) for HRG XA01Z (IC), XA02Z (HD), and XA03Z (SC)



Source: BadgerNet

Special care activity is the most closely linked to overall birth rates, but the reduction in special care activity (9%) is higher than the reduction in live birth rate over the same period (6%). This may reflect changes in care pathways undertaken by all neonatal units in response to NHS England's quality improvement initiative *Avoiding Term Admissions into Neonatal units* (the ATAIN programme),[6] which aims to reduce mother-baby separation by early preventative actions and improving transitional care arrangements.

Transformation of maternity and neonatal services

Maternity transformation

In November 2015, the then Secretary of State for Health announced a national ambition to reduce the number of stillbirths, neonatal deaths, maternal deaths, and brain injuries that occurred during or soon after birth by 20% by 2020 and by 50% by 2030 (subsequently brought forward to 2025 in the NHS Long Term Plan).

In response to this, in 2016, the National Maternity Review published *Better Births*, which set out a five-year view for NHS maternity services in England.[7] It also highlighted a range of challenges facing neonatology, including capacity and workforce issues. It recommended further work to review neonatal services specifically.

Consequently, NHS England commissioned the Neonatal Critical Care Transformation Review (NCCR).

Neonatal critical care transformation

Based on the recommendations of the NCCR, NHS England set out a vision for neonatal services in England:

> *"The vision for neonatal services across England: A seamless, responsive and multidisciplinary service built around the needs of new-born babies and the involvement of families in their care. High quality neonatal care will be networked together across England, to improve outcomes for all families, provide safe expert care as close to their home as possible, and keep mother and baby together while they need care"*[8]

This vision was supported by a series of actions focused on:

- Aligning capacity: investing in neonatal capacity and developing transport pathways.
- Developing the expert neonatal workforce: medical, nursing, and allied health professionals.
- Enhancing the experiences of families: developing and investing in support for families.

[6] *www.england.nhs.uk/mat-transformation/reducing-admission-of-full-term-babies-to-neonatal-units/*

[7] *NHSE (2016). Better births: Improving outcomes of maternity services in England www.england.nhs.uk/publication/better-births-improving-outcomes-of-maternity-services-in-england-a-five-year-forward-view-for-maternity-care*

[8] *NHS England (2019) Implementing the Recommendations of the Neonatal Critical Care Transformation Review*

The action plan also outlined the processes required to implement these changes, including development of local action plans, integration of neonatal services into maternity planning, establishing national reporting of key regional outcomes and developing the Neonatal Implementation Board as workstream 10 of the Maternity Transformation Programme to oversee implementation of this plan.

The NHS Long Term Plan[9] has committed to new investment to support implementation of the NCCR action plan, with commitments focused on:

i. Redesigning and expanding neonatal critical care services (particularly to increase intensive care capacity) to further enhance safety, effectiveness, and the experience of families.

ii. Further developing the expert neonatal workforce required, including:
    - extra neonatal nurses; and
    - expanded roles for some allied health professionals to support clinical care.

iii. Enhancing the experience of families through care coordinators and investment in improved parental accommodation.

About our analysis

Scope of the review

This GIRFT review was commissioned in part to assist the implementation of the NCCR Action Plan and provide further understanding and support to the key challenges facing neonatology. The scope of this GIRFT review is wide-ranging to include data required to support networks and trusts with the action plans needed for the NCCR, as well as exploring possible new areas for action.

The NCCR report recommended neonatal networks and services should produce a gap analysis of medical and nurse staffing, and that workforce transformation was needed, with greater recognition of allied health professional roles. GIRFT has therefore provided detailed benchmarking data against national standards for medical, nursing and AHP workforce as well as a snapshot survey of neonatal services and workforce done in conjunction with Royal College of Paediatrics and Child Health (RCPCH).

GIRFT deep-dive visits to ODNs were prioritised before trust level visits to support the development of regional NCCR implementation plans. These visits were an opportunity for the neonatal ODN teams, transport services and providers of neonatal services to come together with regional maternity and commissioning groups to review organisation and network-level data in depth and share good practice.

These visits were supported by network level data packs, which included information on network organisation and relationships (commissioning, maternity services, providers, and parents), activity and capacity, network pathways and flows, regional neonatal transport services, clinical processes and outcomes, research and governance, parent facilities and involvement in care, and workforce information for medical, nursing and allied health professionals. In addition, the networks received appendices with key data at an individual hospital site level, for parent facilities and family support, and medical, nursing and AHP workforce. Network visits were completed by October 2020, ahead of ODN submission of NCCR implementation plans to the Neonatal Implementation Board in November 2020.

GIRFT visits to trusts commenced in September 2020 and are ongoing, having experienced some disruption due to the ongoing pandemic. Separate trust level data packs have been prepared for surgical NICUs, medical NICUs, LNUs and SCUs covering similar domains to the network packs, but with more granular detail and additional information on reference costs.

[9] *NHS England (2019) The NHS Long Term Plan*

Methodology and data sources

To support and prepare for our network and trust visits, we analysed a range of data collected directly from trusts as well as collating data from existing sources. Our approach included:

- A pro-forma to collate ideas for benchmarking metrics, which was sent out to all neonatologists via the neonatal ODNs in March 2019.
- A snapshot survey of neonatal services and workforce across the whole UK (191 services), done in conjunction with the RCPCH on a weekday and weekend day in September 2019. The goal was to provide an 'on the ground' picture of shortages and day-to-day realities for people working in neonatology. Results from this snapshot were reported back to neonatal services in January 2020 through individual benchmarking reports produced by the GIRFT team and the findings nationally were reported in a joint publication with the RCPCH in September 2020.[10]
- GIRFT questionnaires to neonatal ODNs and neonatal transport services (100% returns, October 2019).
- Four GIRFT questionnaires for each hospital (100% returns December 2020) covering the following areas:
  - medical staffing, clinical services, governance and research;
  - nurse staffing;
  - allied health professionals (AHPs), pharmacy and psychology; and
  - parents and families.

In addition to the surveys described above, our review has drawn on data from a range of other sources. These include:

- BadgerNet, a key data source used by all units to collect data for multiple purposes;
- Hospital Episode Statistics (HES) and Diagnostic Imaging Dataset (DID) data;
- National Neonatal Audit Programme (NNAP) data; a longstanding national clinical audit run by the RCPCH on behalf of Healthcare Quality Improvement Partnership (HQIP);
- MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK), National Perinatal Epidemiology Unit (NPEU), University of Oxford, which provides risk-adjusted stillbirth and neonatal and perinatal mortality data;
- NHS England Quality Surveillance Team compliance scores;
- NHS England Blueteq High Cost Drugs Management System; and
- National Cost Collection Data, NHS Digital.

This review has also drawn on extensive consultation with appropriate expert groups and other clinical specialties where relevant, both in the early development and drafting of the report.

[10] *RCPCH and GIRFT, Snapshot of neonatal services and workforce in the UK www.rcpch.ac.uk/resources/snapshot-neonatal-services-workforce-uk*

Findings and recommendations

Neonatal Operational Delivery Networks

Highly functioning networks are essential to improve outcomes in neonatal care.[11, 12, 13, 14, 15] Neonatology within the UK has been extremely fortunate that networks have been in existence since 2004 and these have developed into mature functioning organisations. The following information, gained from benchmarking data and network deep-dive visits, provides an in-depth review of network organisation, activity and capacity, patient pathways and flows and the regional transport service. Network clinical outcomes are discussed elsewhere in this report.

Network organisation

Funding arrangements

GIRFT key findings:

- There is at least a three-fold difference in core funding across the ten networks when adjusted for service size.
- Lower funded networks are unable to support core network functions as well as those that are better funded.
- LMS/LMNS support to ODNs to implement actions from NCCR is variable.
- Hosting arrangements can make substantive appointments to the network difficult.

Neonatal Operational Delivery Network (ODN) budgets for FY2019/20 totalled nearly £28m, with an average network budget of £277,276. Networks require core funding to support key areas of activity, including near to real-time pathway monitoring, network education and training, quality improvement and parent engagement. GIRFT compared funding, adjusted for service size and showed that there is at ***least a three-fold difference in core funding*** across the ten managed ODNs: Average neonatal ODN budget per 1,000 live births is £5,038 (range £2,500-£7,500) and average neonatal ODN budget per 1,000 admission to neonatal units is £57,342 (range £26,684-£92,057).

There was evidence from deep-dive visits that where network budgets are low, networks have been unable to support core functions as well as those that are better funded. The London network was the most affected by this, receiving half as much funding, relative to activity, compared with the network average. National agreement is required regarding core network funding (relative to network size) to ensure all networks have sufficient and equitable resource to be able to operate effectively across all areas of their remit; this should include data analysis, education, and administrative support requirements in addition to managerial and clinical leads. Arrangements must be future-proofed for changes to funding models and the move to integrated care systems (ICSs). A national neonatal ODN service specification is needed which reflects these core funding requirements.

In 2019 only one network received a small amount of funding from their Local Maternity System (LMS) or Local Maternity and Neonatal System (LMNS) to support the actions from the Neonatal Critical Care Review (NCCR). This has changed in some but not all networks in 2020, exacerbating existing disparities in resource to support implementation of the findings of the NCCR review. Where neonatal ODN and LMS/LMNS work plans align, shared ownership and joint working should occur. Planning guidance to LMSs/LMNSs for 2021/22 makes it clear that LMSs/LMNS must take responsibility for working with neonatal ODNs on implementing the neonatal critical care review.

Neonatal ODNs are hosted through a provider trust. On our visits we heard that the fees charged by hosting trusts vary and this materially affects the amount of funding available for network activities. Several networks also reported difficulties appointing substantive network posts with the current hosting arrangements as hosting organisations do not want to hold financial risk when funding for networks is only secured from year to year. This is a significant impediment to making suitable new appointments to key network positions. The East of England Regional Specialised Commissioning Team resolved this issue by establishing memorandums of understanding with the hosting organisation to underwrite these posts. This allowed substantive appointments to be made, providing much greater stability to the network. All regional specialised commissioning bodies should work with networks and hosting organisations to establish a mechanism to support substantive key network appointments.

[11] *Marlow N, Bennett C, Draper ES, et al. (2014) Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study. Archives of disease in childhood Fetal and neonatal edition*

[12] *Watson SI, Arulampalam W, Petrou S, et al. (2014) The effects of designation and volume of neonatal care on mortality and morbidity outcomes of very preterm infants in England: retrospective population-based cohort study. BMJ Open*

[13] *Lasswell SM, Barfield WD, Rochat RW, et al. (2010) Perinatal regionalization for very low-birth-weight and very preterm infants: a meta-analysis. JAMA*

[14] *Desplanches, T, Blondel B, Morgan AS, et al. (2019) Volume of Neonatal Care and Survival without Disability at 2 Years in Very Preterm Infants: Results of a French National Cohort Study. J Pediatr*

[15] *Walther F, Küster DB, Bieber A, et al (2020) Impact of regionalisation and case-volume on neonatal and perinatal mortality: an umbrella review BMJ Open*

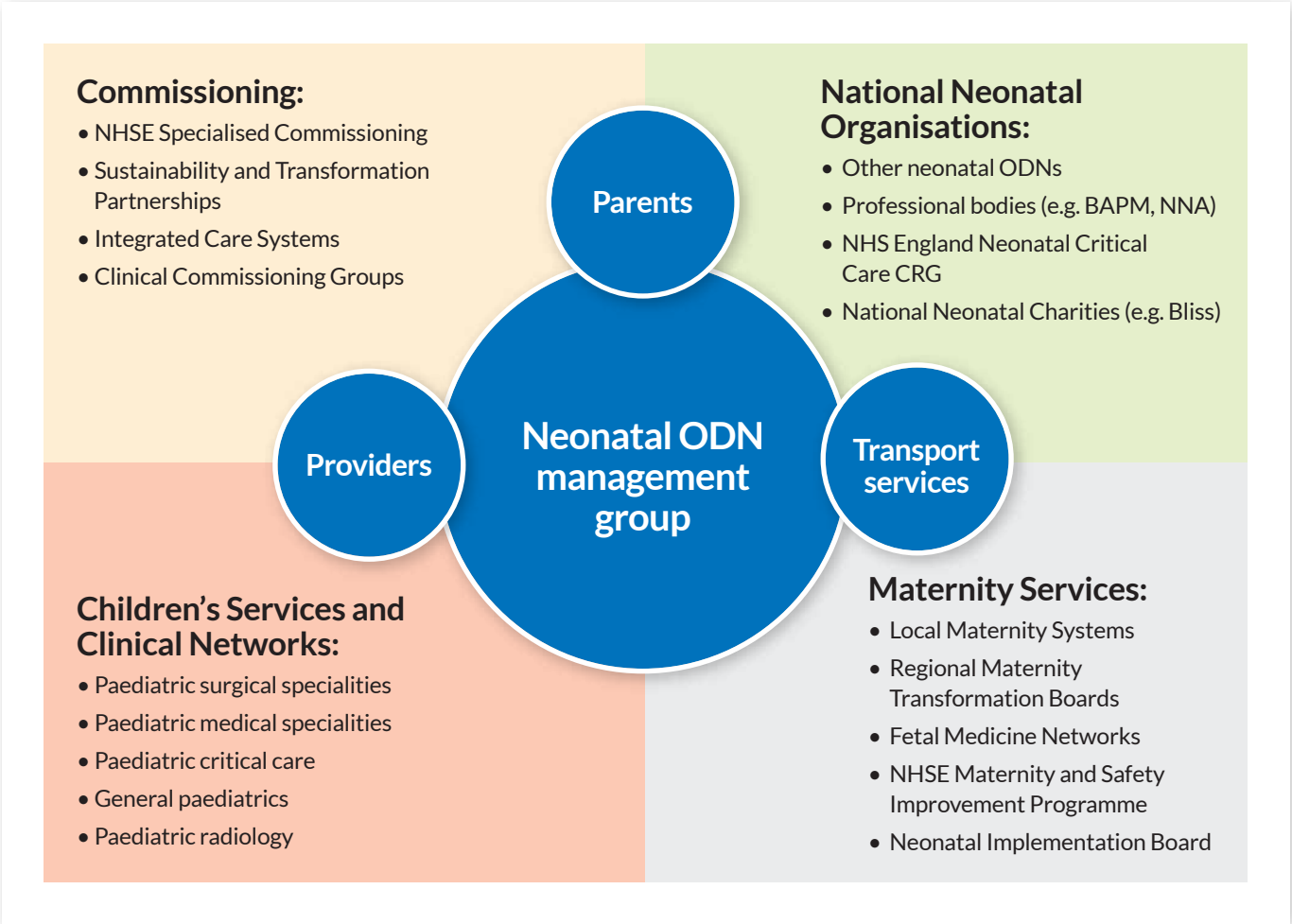
Working relationships

GIRFT key findings:

- Neonatal ODN relationships with service providers are good and have improved further during the pandemic.
- There is significant variation across networks in parent involvement in network activities.
- Neonatal ODN relationships with LMSs/LMNSs and ICSs are hampered by geography which is not co-terminus.
- There is a variable level of support and leadership from regional specialised commissioning teams, particularly around pathway reconfiguration proposals.

Whilst neonatal ODNs are hosted through provider trusts, the network senior management team must work closely with a wide variety of NHS and professional organisations, services, and parent representatives to be effective (**Figure 4**).

Figure 4: Neonatal ODN: Key Relationships



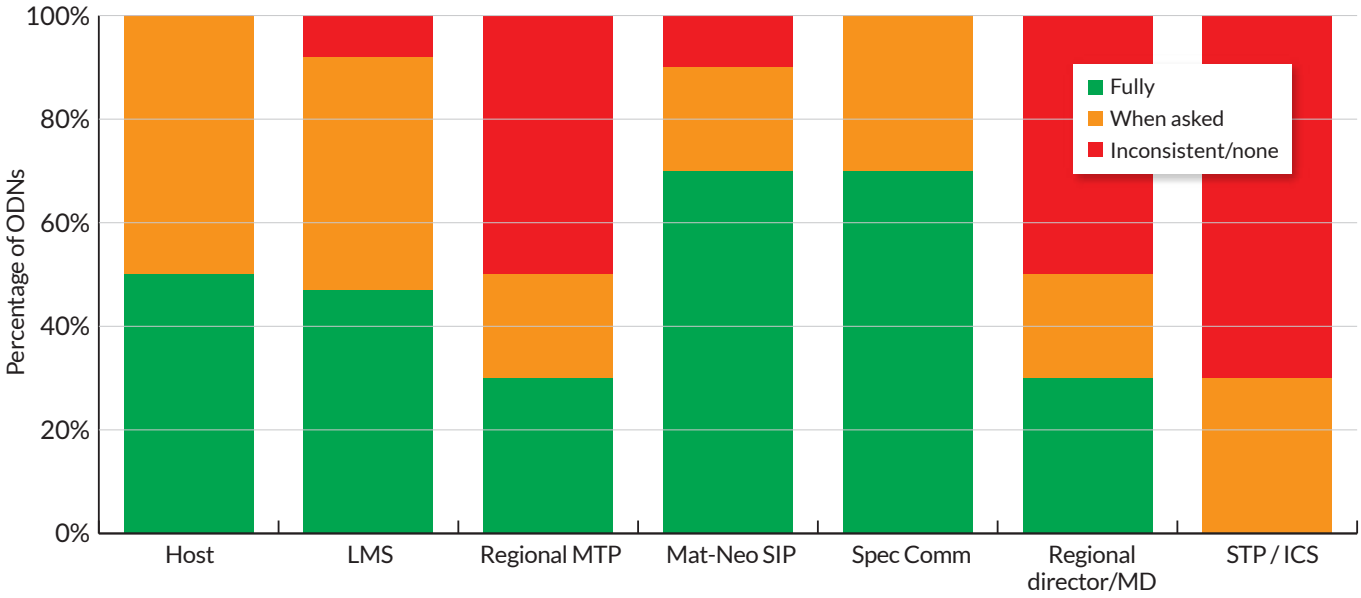
Source: GIRFT

Relationships with service providers (Neonatal Intensive Care Units - NICUs, Local Neonatal Units - LNUs, Special Care Units - SCUs and transport services) were good across nearly all networks. Networks reported further improvements in engagement with network meetings since the pandemic with video conferencing and telemedicine links making attendance easier, particularly for smaller services. Medical and nursing representation was widespread, however, allied health professionals, pharmacy and psychology involvement in networks was much more variable (discussed in the GIRFT Neonatology Workforce report).

There is variation across the networks in the involvement of parents in network activities. Parents are key partners in neonatal care and there needs to be a continued focus on parental involvement to ensure this is embedded into all aspects of network work (this is discussed in more detail in the *Supporting families* section of this report).

GIRFT data and discussion at deep-dive visits suggests that relationships with Local Maternity Services (LMS) and regional Maternity Transformation Partnerships (MTP) were not optimal for most networks. In addition, only 60% neonatal networks had maternity representation on the neonatal network board. There were poor relationships with STPs and ICSs across all networks, and there was variable access to specialised commissioning regional directors /medical directors (**Figure 5**).

Figure 5: Level of engagement between neonatal ODNs and maternity and commissioning structures



Source: GIRFT Network Questionnaire, October 2019

Relationships between neonatal and maternity services are vital to provide optimal perinatal care pathways and improve outcomes. From our deep-dive visits, it is clear there have been improvements in linkage between some (but not all) neonatal networks and LMSs, some of which have evolved to become LMNSs. However, there remain some difficulties with this relationship. This is partly because the neonatology and maternity interface is predominantly focussed on the higher risk pregnancy, which forms just one aspect of a wider maternity programme. But also, the footprints are not co-terminus with neonatal network pathways and each network has between three and six LMSs/LMNSs in their region, with limited resource to attend multiple LMS/LMNS meetings. Some LMSs/LMNSs have recognised this and provide funding for local neonatal representation at the LMSs/LMNSs, and/or maternity representation at neonatal network board/governance and mortality review meetings.

Moving forwards, neonatal ODN relationships with LMSs/LMNSs and the newly formed Fetal Medicine Networks (FMNs) must be strengthened. The footprints for these organisations should be aligned as much as possible together with a similar collective ICS footprint. An overarching regional high-risk perinatal group would allow streamlining of joint maternity and neonatal objectives.

There has, thus far, been relatively less involvement between neonatal ODNs and the more recently formed paediatric clinical networks. Moving forwards, it will be important to develop closer relationships with these networks and specialist services, embedding paediatric medical and surgical subspecialty input into antenatal and postnatal pathways across the network. This applies particularly to paediatric surgery, cardiology, neurosurgery, respiratory, ophthalmology and paediatric critical care. Where pathways cross geographic boundaries, inter-ODN collaboration is strongly encouraged to ensure effective and consistent models of care.

Although relationships with NHS England regional specialised commissioning teams were felt to be good by most networks, during deep-dive visits it was apparent that this relationship was much more supportive for some networks than others, particularly around resolution of governance issues and leadership to develop the business case for service change and subsequently support any reconfiguration/re-designation of services. Strong commissioning leadership is key to ensuring neonatal and maternity services continue to evolve to provide the best quality care across the region.

Neonatal transport services

GIRFT key findings:

- A significant proportion of services are unable to comply with transport benchmark standards.
- Less than one third of services met the 1-hour mobilisation time for time critical transfers in 95% cases in 2019/20.
- Only 72% of services were able to transfer over 95% babies in catchment who required an uplift in care.
- In three networks, inadequate transport service provision significantly impacts patient flow.
- Charitable funding is the primary funding stream for transport equipment in 36% of services.
- Consultant availability to perform transfers was not present 24/7 for 45% of services.

Neonatal transport service provision is critical to network functioning, ensuring expert clinical support for babies who require transfer for higher levels of neonatal care (uplifts) according to network pathways, as well as repatriating babies to their local hospitals when higher levels of care are no longer required. They also provide valuable input to network governance and morbidity and mortality reviews and participate in regular national benchmarking and quality improvement through the UK Neonatal Transport Group (NTG).[16]

All networks have a single transport service provider, operating out of one to three hubs, except for the South West which has two services (currently under review). Operating models vary: five services are co-located with NICUs, four are standalone neonatal services and two are standalone paediatric and neonatal services. Eight have bespoke ambulance services with a further service working to remove reliance on the regional emergency services due to difficulties accessing ambulances promptly. The Northern network, however, continues to have an excellent service provided by the regional ambulance provider.

These services transferred 13,224 babies in 2019/20, of which nearly 6,500 were for uplift in care. National benchmarking requirements are set out in the neonatal critical care transport service specification.[17] Benchmark data shows that a significant proportion of services are unable to comply with these standards.[18]

- 72% of transport services transferred at least 95% of patients requiring transfer for uplift within its defined catchment area on an annual basis.
- 36% of transport services met the 1-hour mobilisation time for time-critical transfers in 95% of cases annually.
- 82% of transport services met the referral response time to arrive within 3.5 hours of the referring call for uplift transfers for intensive care in 80% of cases annually.

[16] *http://ukntg.net/*

[17] *https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e08-serv-spec-neonatal-critical-transp.pdf*

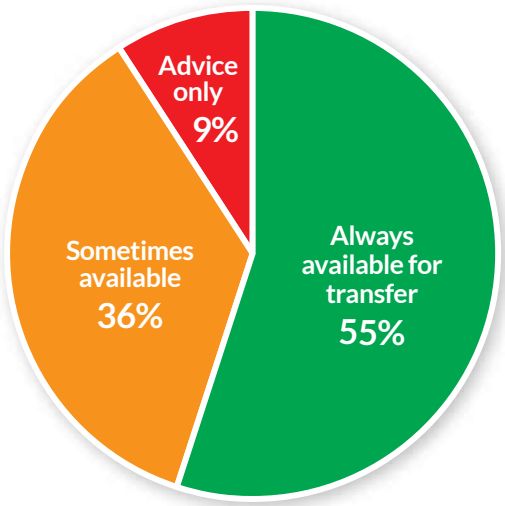
[18] *National Transport Group (NTG) benchmark data, 2019/20*

This is of significant concern and networks and commissioners should review transport services where service specification response times are consistently not met. GIRFT found there were three networks where inadequate transport service provision was causing substantial delays in transportation and/or requiring local hospitals to provide ad hoc transport services of their own on a regular basis. Problems were related to ambulance service provision and/or clinical hours of service. There have been some changes following GIRFT visits and the impact of these will require careful monitoring. Failure to provide sufficient transport service provision has an impact on the timeliness of transfer for specialist intensive care services as well as delaying repatriation closer to home. This has a knock-on impact on capacity, particularly intensive care capacity. Any changes to network pathways or configuration must be carefully analysed to understand the impact on transport services.

There is lack of clarity regarding funding for some aspects of transport service, particularly where services are integrated with NICUs. There is a particular issue with capital funding for transport equipment with charitable funding the primary source of funding for four (36%) services. Given the cost and specialist nature of the equipment, a more secure funding source is needed, and capital funding should be included in funding allocations.

There are some staffing concerns, particularly around the availability of consultant staff to perform transfers due to gaps in funding (**Figure 6**). Some services are also struggling with middle-grade medical rotas for transport, and this will need review alongside network-wide workforce transformation plans (see also the GIRFT Neonatology Workforce report).

Figure 6: Consultant availability for performing neonatal transport



Source: Transport Service Questionnaire, October 2019

Capacity and activity

Network capacity

GIRFT key findings:

- There are significant NICU capacity constraints which are most severe in North, Central and East London, South London, East Midlands, Yorkshire and Humber, South West and Northern networks.
- There is a six-fold difference in network rates of preterm infant capacity transfers for babies 27-34 weeks' gestation in the first three days of life.
- 42% of NICUs have combined IC/HD cot occupancy levels above 80%.
- A further 32 IC/HD cots and 16 SC cots are required in NICUs to manage current activity at cot occupancy levels 80% or less.
- Deficits in IC/HD cots are highest in South London and North, Central and East London,
- Deficits in total cots are highest in Yorkshire and Humber, South West, North, Central and East London and East Midlands.

Networks must have capacity to manage at least 95% of babies born to women booked for delivery in the network (excluding agreed tertiary transfer pathways out of network e.g. for surgery).[19] This can be difficult to measure for the whole population due to difficulties ascertaining women's booking hospitals, which may change several times. However, it is possible to obtain a reasonable assessment of this measure for the preterm population born at 30 weeks' gestation or less, as these babies will almost always transfer back to their local hospital before being discharged home.

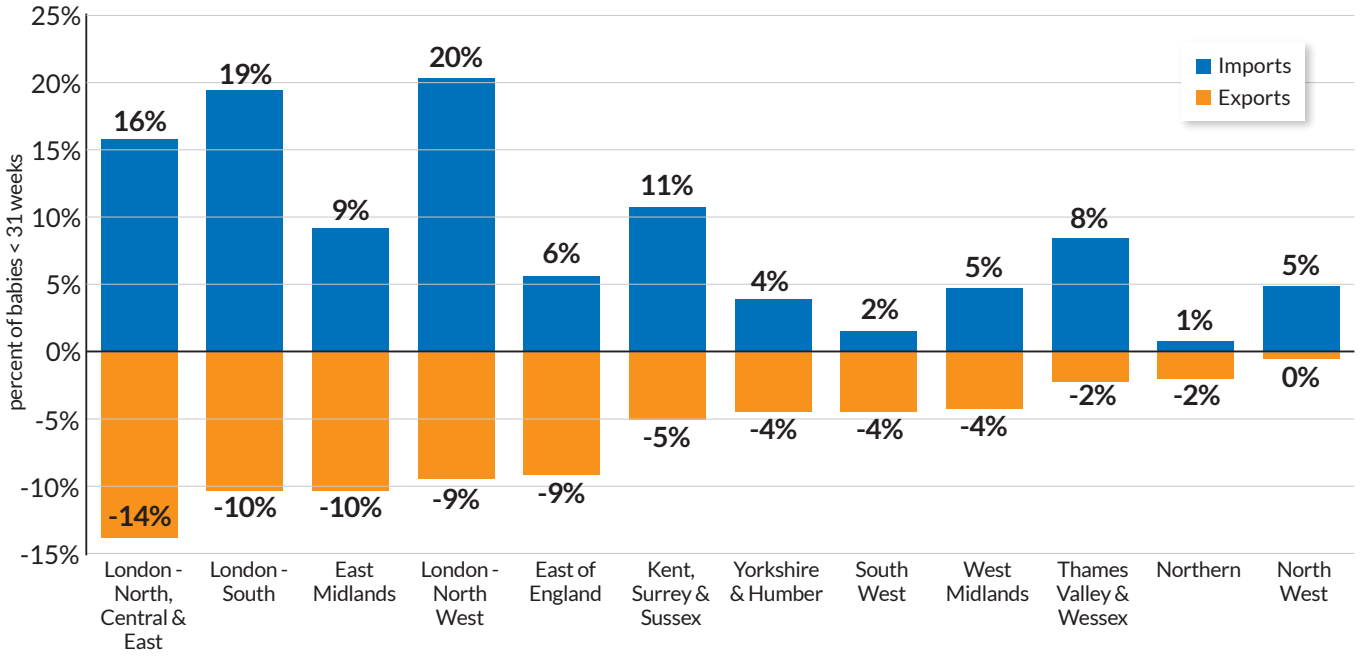
We reviewed preterm babies that were ***imported*** to the local network from other networks, and local babies that were ***exported*** from the local network to other networks (all babies following tertiary pathways were excluded), summarised in **Figure 7**.

The ability of networks to care for local preterm infants (<31 weeks) within network (excluding transfers out for tertiary care) ranges from 86% to 99.5%. The data shows that:

- Networks in London, East Midlands and East of England have a high proportion of local babies being managed in other networks.
- North West, Northern, and Thames Valley and Wessex manage almost all local preterm babies within their own network.
- London networks also have the highest proportions of babies being imported into their networks from other networks, which suggest significant movement between the three London networks for capacity reasons (tertiary referrals from East of England and Kent, Surrey and Sussex regions, which are known to flow into London, are excluded from this data).
- South London, North West London, Kent Surrey and Sussex, Thames Valley and Wessex and North West import higher proportions of babies than they export.

[19] *NHS England Neonatal Critical Care Specialised Services Specification (E08) https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08/*

Figure 7: Percentage of babies <31 weeks gestation who were a) exported from the network and (b) imported to the network



Notes:
- Movement in or out of network for tertiary referrals has been excluded.
- Exports are babies who were discharged home from the local network but did not receive all their care in that network.
- Imports are babies who were born in the network but were discharged home from another network.

Source: BadgerNet MY2018/19

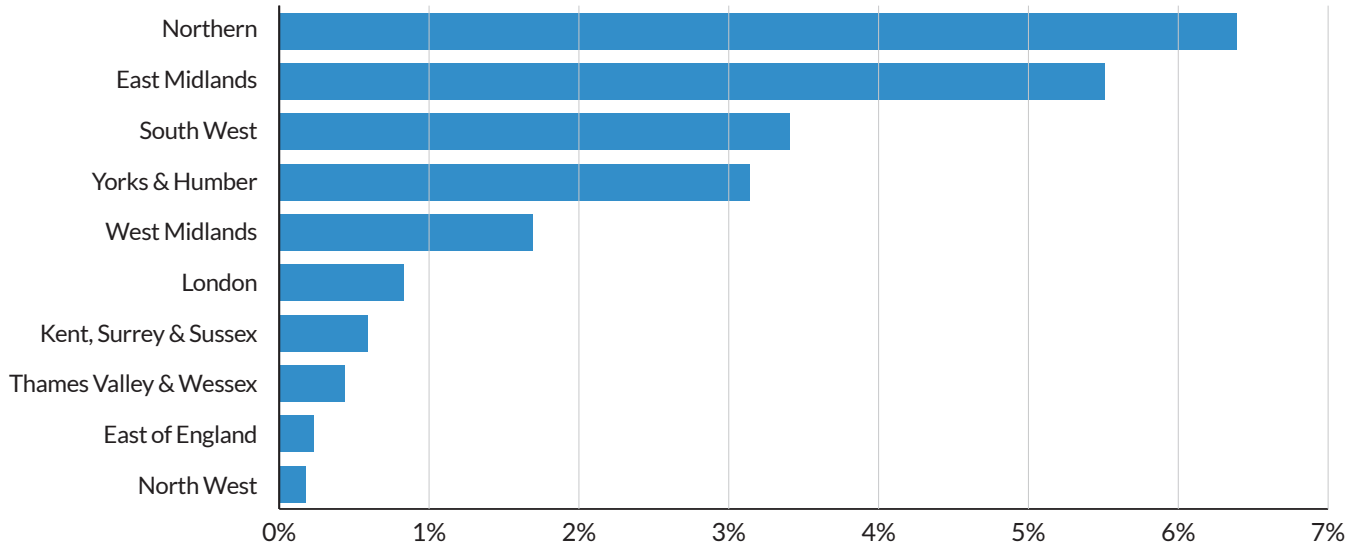
Whilst the above data gives a picture of total network capacity for managing the preterm population, this may mask capacity issues within the network. There is no data for in-utero transfers, but ex-utero capacity transfers (in or out of region) are monitored by the regional transport services. Ex-utero transfers for capacity reasons for babies <27 weeks are fortunately low (five in total in 2019/20) as there are known mortality and brain injury risks associated with transfers in this age group.[20, 21] However, there is a six-fold difference in the proportion of preterm infants between 27-34 weeks' gestation admitted to networks who required a transfer for capacity reasons in the first few days of life (**Figure 8**). This is concerning given the known increased morbidity and mortality risks associated with early transfer in the more preterm infants in this group, as well as the significant negative impact on family experience across the gestational age range.

Whilst the Northern network transfers few babies out of network, there are nonetheless very significant capacity issues in the region and there has been some additional IC capacity opened since this data was collected, which has had a significant positive effect. There are also significant capacity pressures in East Midlands, South West and Yorkshire and Humber. It should be noted that the capacity transfer figures for London are underrepresented as these transfers are often performed by local teams due to capacity constraints on this transport service.

[20] *Helenius K, Longford N, Lehtonen L, Modi N, Gale C. (2019) Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching BMJ*

[21] *Redpath, S., Shah, P.S., Moore, G.P. et al. (2020) Do transport factors increase the risk of severe brain injury in outborn infants <33 weeks gestational age? J Perinatol*

Figure 8: Capacity transfers as a proportion of admissions for infants 27-34 weeks gestation

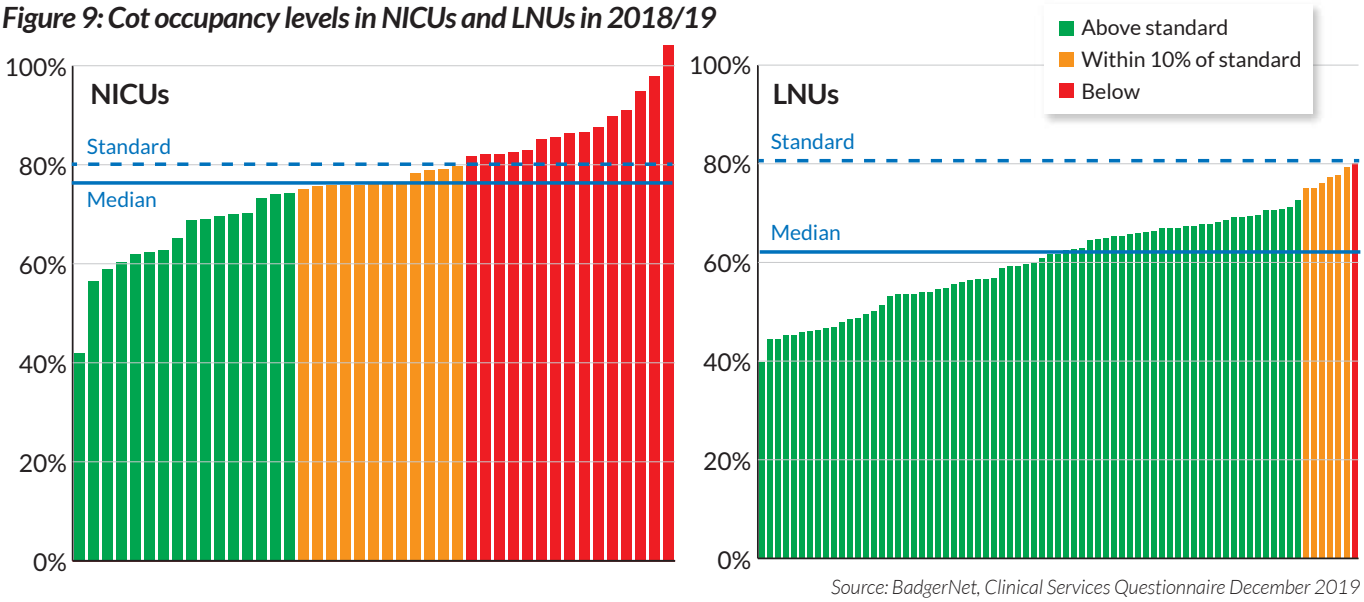


Source: National Transport Group Data and BadgerNet Jan-June 2019

Neonatal unit capacity

National service standards state that staffing should be based on average unit occupancy of 80% to allow for natural peaks and troughs in activity.[22, 23, 24] **Figure 9** demonstrates significant capacity issues in NICUs – median NICU cot occupancy is 78% for both total cots and intensive care/high dependency (IC/HD) cots, 15 NICUs (35%) have total cot occupancy levels above 80% rising to 42% for combined IC/HD cots; two units were on average over 100% occupied across the year. For LNUs and SCUs the picture is better. Median total cot occupancy is 61% for LNUs and 45% for SCUs. One LNU and no SCUs had total occupancy levels over 80%; five LNUs (7%) were above 80% occupancy for IC/HD cots.

Figure 9: Cot occupancy levels in NICUs and LNUs in 2018/19



Source: BadgerNet, Clinical Services Questionnaire December 2019

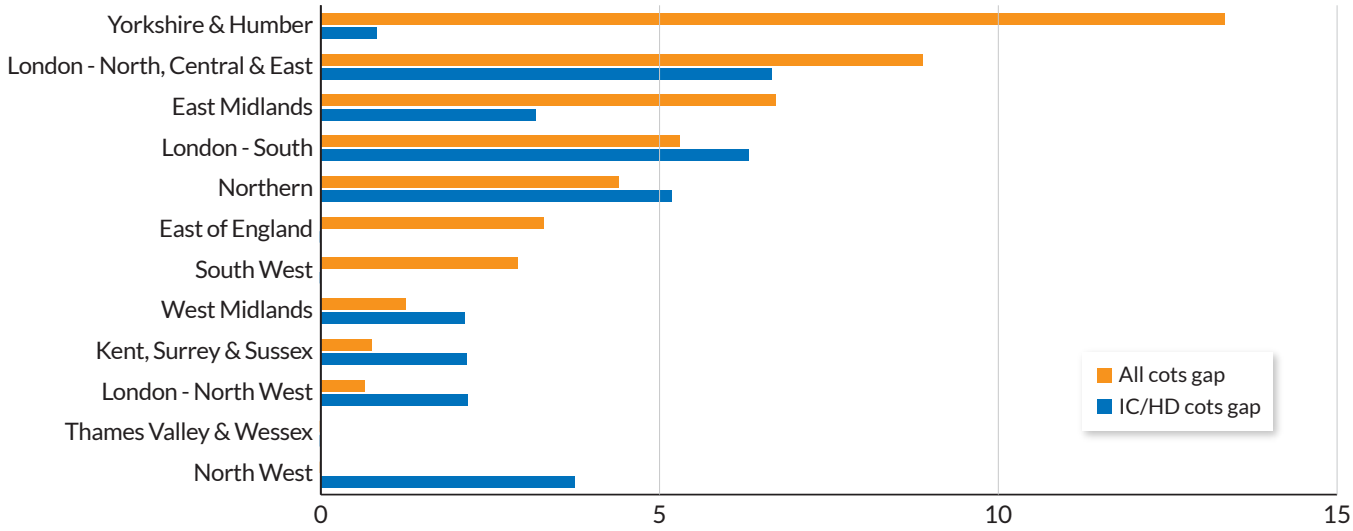
[22] *NHS England Neonatal Critical Care Specialised Services Specification (E08) https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08/*

[23] *Department of Health (2009) Toolkit for high quality neonatal services http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/Toolkit-2009.pdf*

[24] *NHS Improvement (2018) Safe, sustainable and productive staffing An improvement resource for neonatal care https://improvement.nhs.uk/documents/2978/Safe_Staffing_Neonatal_FINAL_PROOF_27_June_2018.pdf*

To provide the same level of activity at recommended cot occupancy levels (based on 2018/19 activity), a further 32 IC/HD cots and 48 total cots are required in NICUs and 3 additional IC/HD cots but no increase in total cots in LNUs. The NICU cot requirement is not evenly distributed across networks. Where the IC/HD cot gap is larger than the total cot gap, there are SC cots with a lower occupancy but these are not available for IC/HD care. Large gaps in total cot occupancy but small gaps in IC/HD provision suggest a deficit of SC cots for the local population. This can also result in IC/HD capacity issues due to overspill of special care patients into these cots (**Figure 10**).

Figure 10: Additional IC/HD cots and additional total cots required in NICUs across ODNs to support current activity



Source: BadgerNet, Clinical Services Questionnaire December 2019

These calculations do not take into consideration any alterations to pathways which have occurred due to lack of capacity. For example, in the South West neonatal ODN, due to high transfers of patients out of Bristol to accommodate network intensive care patients, local network capacity modelling suggests the total additional cot requirements changes from 3 SC to 11 SC and 1 IC/HD. All networks are undertaking further capacity modelling locally as part of the NCCR. This should be done with local neonatal transport services and consider existing local pathways of care, repatriation of activity from out of network and any planned changes to unit designation or pathways. Networks will produce an accurate capacity plan for regional approval and review at the Neonatal Implementation Board. These plans will likely require further investment to support delivery

Activity

GIRFT key findings:

- 42% of NICUs and 39% of LNUs do not meet NCCR activity standards.
- 31% of both NICUs and LNUs are >10% below the standard.
- 17% of NICU IC activity and 15% of LNU IC/HD activity occurs in units that are >10% below the standard.
- Increased IC and IC/HD capacity in a smaller number NICUs and LNUs will be required to support service reconfiguration.
- There is a strong correlation between live births and IC/HD activity in LNUs; <3000 live births do not generate enough activity to warrant an LNU, 3,000-5,000 live births may require an LNU or SCU, >5,000 births require an LNU as a minimum.

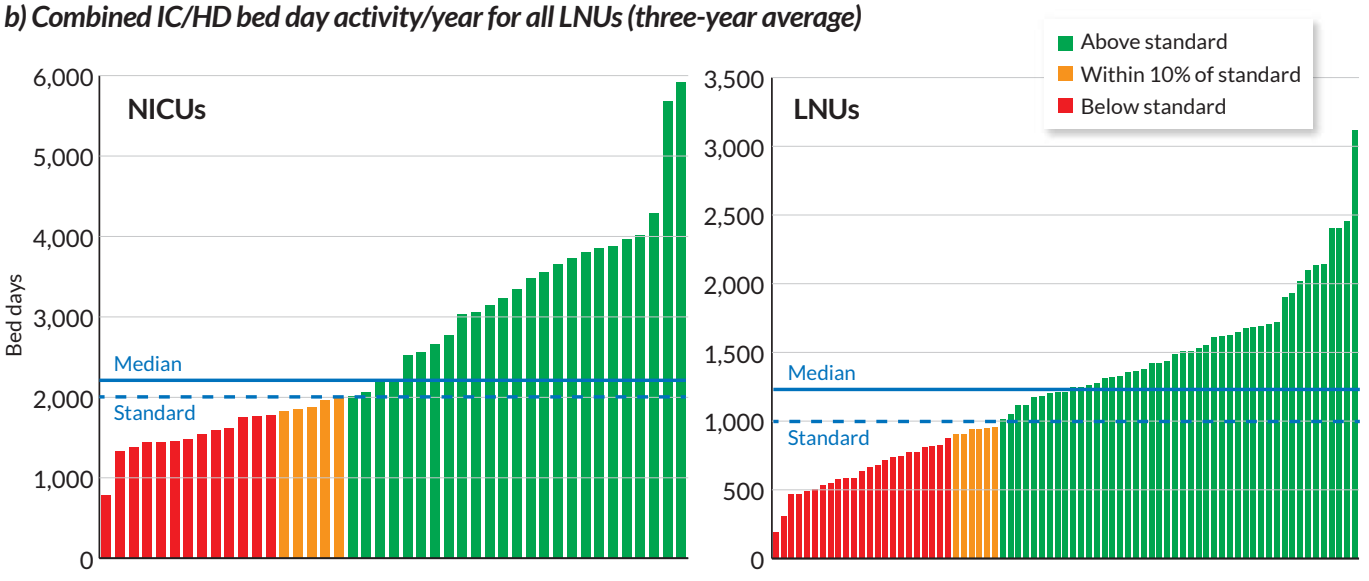
There is strong evidence that a higher volume workload, particularly for the most premature infants, is associated with improved outcomes.[25, 26, 27, 28, 29] The NCCR recommends that:[30]

- All NICUs should do more than 2,000 IC bed days per year (2016 HRGs) and look after at least 100 very low birth weight (VLBW) infants per year, unless geographically challenging.
- All LNUs should undertake a minimum of 500 bed days of combined IC/HD care intensive per year (2016 HRGs), with services providing ongoing HD care expected to have higher levels of activity, working to provide at least 1000 combined IC/HD bed days per year.

Reviewing average activity over a three-year period from 2016-19, there is very wide range of IC and HD activity occurring in NICUs and LNUs with 42% of NICUs and 39% of LNUs not meeting the standards (**Figure 11**). Just under a third of both NICUs and LNUs had activity levels that were more than 10% below the standard and these units managed 17% of IC in NICUs and 15% of IC/HD activity in LNUs. Five (6%) LNUs did not meet the 500 IC/HD bed day standard (2% IC/HD activity in LNUs). A small number of NICUs/LNUs are in more remote locations. Most NICUs (81%) looked after 100 or more VLBW infants in 2018/19.

The results for NICUs are a slight deterioration from findings in the NCCR data review (36% did not meet standard in 2014-16, compared with 42% in 2016-19) (**Table 2**). Given that capacity challenges are mostly concentrated in the high-volume NICUs, it is not surprising that this situation is relatively unchanged. Any changes in configuration of NICUs or LNUs must be managed very carefully to ensure there is sufficient capacity across the whole system to support this. Several networks have successfully used data from GIRFT reviews to support business cases for urgent additional capacity e.g. the Northern network. The NHS Long Term Plan commits to addressing shortages in neonatal capacity through increased intensive care cots. This increase will be essential to support networks and neonatal services to provide the best service configuration to improve survival, safety, and the quality of care for babies.

Figure 11: a) IC bed day activity /year for All NICUs (three-year average)
b) Combined IC/HD bed day activity/year for all LNUs (three-year average)



Source: BadgerNet MY2016-19

[25] *Marlow N, Bennett C, Draper ES, et al. (2014) Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study. Archives of disease in childhood Fetal and neonatal edition*

[26] *Watson SI, Arulampalam W, Petrou S, et al. (2014) The effects of designation and volume of neonatal care on mortality and morbidity outcomes of very preterm infants in England: retrospective population based cohort study. BMJ Open*

[27] *Lasswell SM, Barfield WD, Rochat RW, et al. (2010) Perinatal regionalization for very low-birth-weight and very preterm infants: a meta-analysis. JAMA*

[28] *Desplanches, T, Blondel B, Morgan AS, et al. (2019) Volume of Neonatal Care and Survival without Disability at 2 Years in Very Preterm Infants: Results of a French National Cohort Study. J Pediatr*

[29] *Walther F, Küster DB, Bieber A, et al (2020) Impact of regionalisation and case-volume on neonatal and perinatal mortality: an umbrella review, BMJ Open*

[30] *NHS England and NHS Improvement Implementing the recommendations of the National Critical Care Review*

Table 2: Summary of activity standards (three-year average) for NICUs and LNUs

	Meets NCCR activity standard (≥2000 IC/HD)	Does not meet NCCR activity standard (≥2000 IC/HD)	
NICUs		**Within 10% NCCR standard**	**>10% lower than NCCR standard**
Number of NICUs	25 (58%)	5 (11%)	13 (31%)
% Total NICU IC activity	75%	8%	17%
IC cots at 80% occupancy	290	33	66

	Meets NCCR activity standard (≥1000 IC/HD)	Does not meet NCCR activity standard (≥1000 IC/HD)	
LNUs		**Within 10% NCCR standard**	**>10% lower than NCCR standard**
Number of LNUs	46 (61%)	6 (8%)	23 (31%)
% Total LNU IC/HD activity	79%	6%	15%
IC/HD cots at 80% occupancy	250	19	49

Source: BadgerNet, MY2016-19

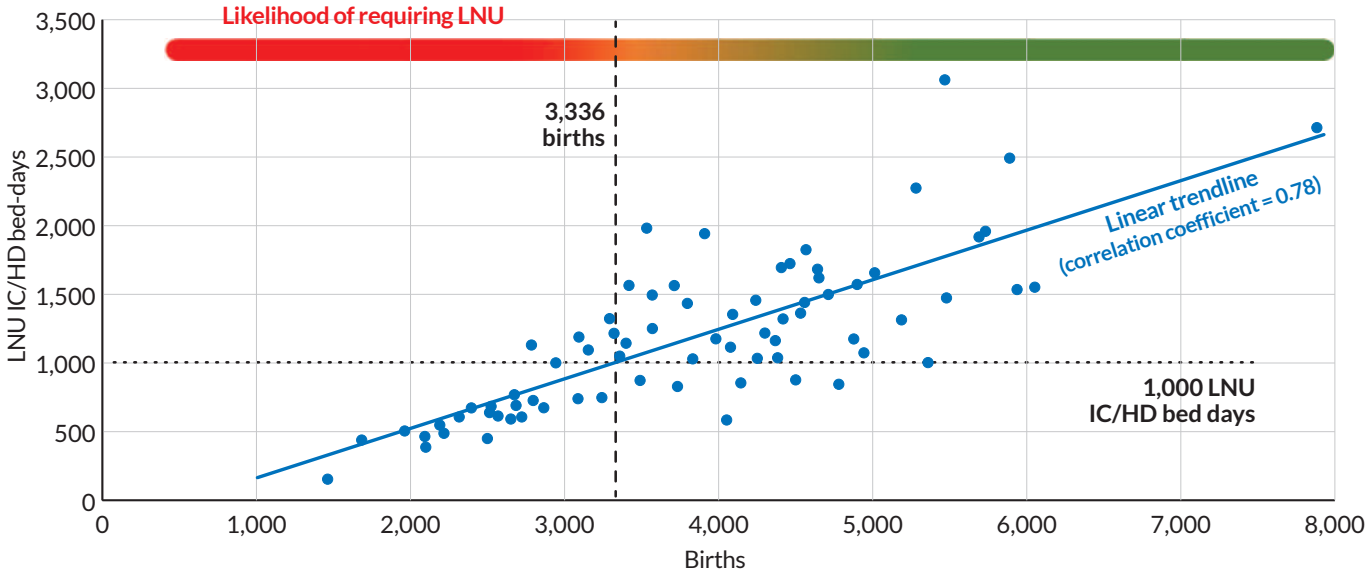
Size of maternity service and neonatal activity

It is important to ensure that care is delivered as close to home as possible, whilst also ensuring that if HD care is to be provided locally, there is sufficient activity to support best quality care. GIRFT examined the relationship between live births and neonatal IC/HD activity in existing LNUs to determine what sized maternity units are likely to result in sufficient local neonatal activity to require an LNU. (Note we have not completed this analysis for NICUs as much of their IC/HD activity is not for the local population).

We found a strong correlation between maternity size and annual neonatal IC/HD bed days of activity (**Figure 12**). Ninety percent of units with 3,000 births or less (21 units) did not have activity that was high enough to warrant ongoing LNU services, a third of units with 3000-3500 live births, and one in six units with between 3500-5000 live births did not have sufficient activity for an LNU, whereas all units >5000 births had sufficient activity. Whilst there is clearly some variation, this data suggests that units with <3,000 births do not generate sufficient local activity to support an on-site LNU, birth rates between 3,000-5000 may require either an LNU or a SCU dependent on local factors, whilst live birth rates >5000 require an LNU as a minimum (**Figure 13**). Currently there are four SCUs with >4,000 births, with definite plans for two of these units to become LNUs and a third is under review.

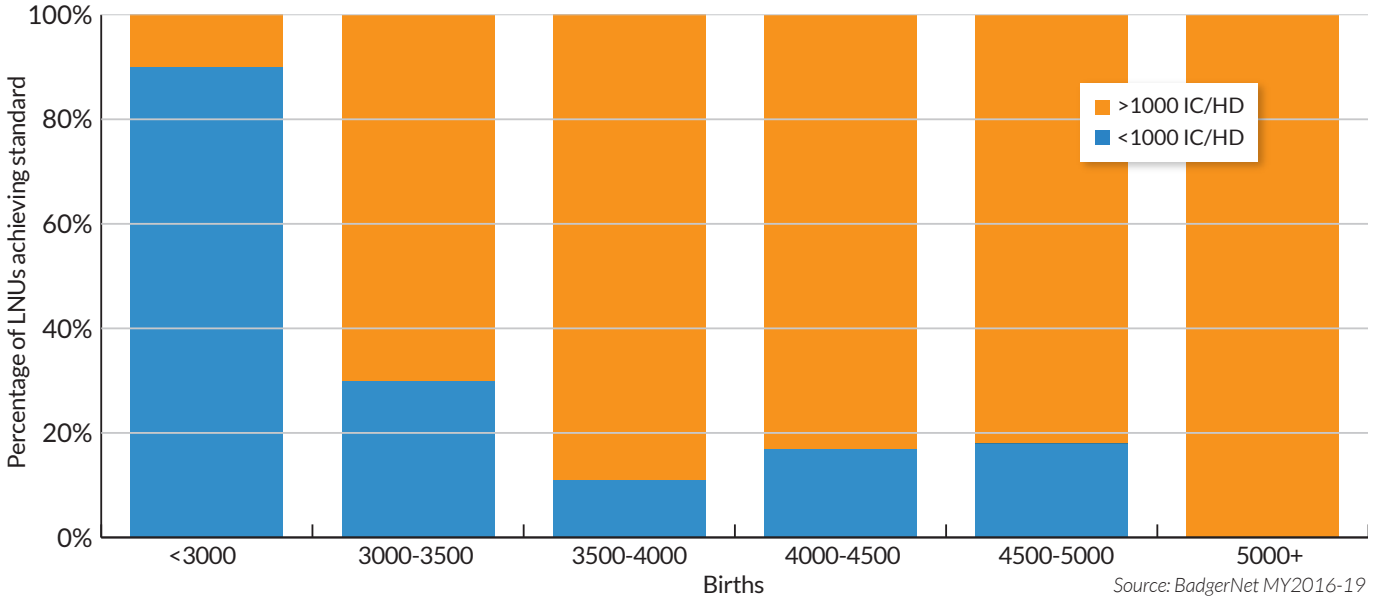
Neonatal ODNs and LMSs/LMNSs should consider this information, alongside local demographic and socioeconomic characteristic which may influence underlying levels of need, when evaluating whether an LNU or a SCU is more appropriate.

Figure 12: Relationship between live births (three-year average) and combined IC/HD bed days



Source: BadgerNet MY2016-19, Clinical Services Questionnaire December 2019

Figure 13: Proportion of LNUs achieving NCCR IC/HD volume standards compared with live births



Source: BadgerNet MY2016-19

Activity and capacity: conclusions

Significant capital investment is needed alongside reconfiguration of services to improve quality of care and patient outcomes. Clarity regarding the amount of capital funding available in the NHS Long Term Plan for additional cot capacity is required. Any critical gaps with no identified funding commitment will need to be escalated through regional specialised commissioning teams and ICSs for national review. The capital funding model is changing within NHS England and clarification is required regarding how additional cots will be funded as the neonatal intensive care footprint is larger than the ICSs.

It was apparent from GIRFT visits that where ODNs and trusts faced challenges with regards to increasing capacity, there was a lack of clarity about how to move this forward. Where neonatal ODNs and regional teams identify a clear need for increased capacity within a trust, particularly where this may involve capital development, ODNs, trusts, and regional commissioning teams must ensure there is an action plan for implementation, including current mitigations and escalation plans if difficulties are encountered.

Where reconfiguration is required, this must be led by specialised commissioning through development of a business case for service change and support for reconfiguration/redesignation of services. Planning such a change must consider the capacity difficulties currently being experienced and mitigations that may be required until capacity can be increased; maternity unit size and any planned reconfiguration or changes to birth rates; and any special circumstances such as remote location (very few locations in England). ODNs must also analyse the likely impact of any changes to network pathways or configuration on transport service capacity and responsiveness.

IN PRACTICE

Experience of reconfiguration of NICUs

Northern Neonatal Network

The Northern Neonatal Network has around 30,000 livebirths per annum and historically had four NICUs in Newcastle, Sunderland, Middlesbrough and North Tees. The network recognised this was too many for the region, resulting in issues with workforce and non-compliance with standards such as being unable to meet the minimum activity required in two NICUs. Although there was agreement in principle to the need for redesignation, agreeing the future designation was much harder. The network approached the regional specialised commissioning team, with a recommendation to commission an independent external review of the NIC services, this was carried out by the RCPCH in mid-2015, who recommended: 1. a single independent standalone transport service; 2. redesignation of North Tees from a NICU to a SCU; 3. Change of service provision at NICU in Sunderland (from 26 weeks); and 4. increased capacity in Newcastle (NICU).

The main challenges were at two levels. The first was reaching trust-level agreement to redesignate North Tees from NICU to SCU, and then approval at the regional Oversight and Scrutiny Committee (OSC). The second was migration of workforce (consultants and nurses) from North Tees to Middlesbrough once redesignation was complete. The third element was achieving consensus with the maternity network due to increase in activity at the three NICUs. The network engaged with all stakeholders, including the regional specialist commissioners, trust CEOs, medical directors, councillors at OSC meetings, Health and Safety Board, local clinicians, the paediatric and maternity networks. It was agreed that one of the essential requirements for the success of redesignation was relocation of neonatal consultants and nurses to the Middlesbrough NICU. This was achieved with little fallout as almost every 'first choice' preference for future work bases across the two sites was achieved. This, and a comprehensive induction and full support package including a 1:1 'buddy'/mentorship to the nurses moving to the larger NICU, was pivotal.

The case for change was made on grounds of safety and quality. To minimise disruption and be realistic about funding and staffing, the changes were phased. The standalone transport service was developed to cope with the potential increase in transfers as a result of re-designation at North Tees. The model developed was an ANNP-delivered service. This was followed by re-designation of North Tees to a SCU. The first stage involved North Tees looking after babies from 28 weeks. This also included developing a joint consultant rota between North Tees and Middlesbrough while simultaneously upskilling the paediatricians to look after SCU neonates. Six months later, neonatologists and nurses from North Tees wanting to work at the NICU were absorbed by the NICU in Middlesbrough. This was a tremendous challenge, but one embraced by all and thus ultimately successful.

The next phase was expansion of capacity at Newcastle, which was consistently over 100% occupancy. This was again undertaken in two stages. The first stage was completed with a 25% increase in IC cots. The second stage is underway, with the aim to further increase capacity at Newcastle to achieve an average 80% occupancy with BAPM nursing standards, while simultaneously changing the service provision at Sunderland to look after babies from 26 weeks' gestation. This is not strictly in accordance with either a NICU or LNU, but a model pathway agreed as per the RCPCH recommendation. The network accepts that the model may need to further adapt to the more recent NCCR recommendations in the longer term.

The main challenges were agreement at the Oversight and Scrutiny Committee, negotiation with trusts and clinician acceptance. Phasing the changes was another key factor in not needing public consultation, especially as the changes were being made on safety and quality grounds. Other key factors included regular negotiations with all stakeholders, the full support of regional specialist commissioners, strong leadership and the need for transparent, consistent and honest communication – which was challenging at times. Collectively the network agrees that the benefits have been extensive and apparent, well worth the challenges encountered along the way, benefitting parents, families, and babies enormously as a result.

Network pathways

High-risk preterm infants

GIRFT key findings:

- 25% of networks met the NHS England standard to have >85% of all high-risk infants born in a NICU in MY2018/19 (range 62-90%).
- There is wide variation across networks in babies born in or transferred to NICUs in the first week of life (88-99%).

The pathway for high-risk preterm infants has been well delineated in the Neonatal Service Specification[18] and is based on evidence, both from the UK and internationally, for significantly reduced mortality and morbidity if high-risk preterm infants are managed in NICUs with a high volume of activity. The best outcomes are associated with birth in the NICU (80% reduction in the odds of neonatal death for babies with birthweights <1000g if born in NICUs compared with births outside these centres).[24, 25, 27]

Action on Neonatal Mortality was issued by NHS England Specialised Commissioning to all LMSs/LMNSs in August 2017, strongly encouraging LMSs/LMNSs and neonatal ODNs to improve the number of high-risk preterm infants (defined as singletons born before 27 weeks, multiples <28 weeks or birth weight <800g) born in a NICU with a target of 85% for each region. This was achieved across all high-risk preterm infants in three networks for MY2018/19 (Figure 14). National Neonatal Audit Programme (NNAP) data, available for infants <27 weeks' gestation born in a NICU for calendar years 2018 and 2019, show similar results, ranging from 60-88% across English networks. However, there was only a very small improvement in overall results across the UK from 74.3% in 2018 to 77.5% in 2019, although there were notable improvements in parts of London and Kent, Surrey and Sussex.[31]

Care pathway decisions at the limits of viability can be difficult and there is an excellent BAPM Framework to support a coordinated approach across neonatology and maternity towards antenatal counselling and informed decisions for families based on a risk matrix as well as guidance for obstetric and neonatal teams to support both survival focused and comfort focused care.[32]

Findings from network visits and published evidence suggest the following actions have been effective for increasing antenatal transfer:[33]

- Improved maternity and obstetric awareness of the importance of in-utero transfer for these high-risk cases.
- Simplify and make it easier for clinicians to arrange antenatal transfers including strategies such as:
  - Single call for the referring clinician to activate the transfer.
  - Bed-finding services for mothers and babies needing in-utero transfer. This was available in 60% networks in 2019, increasing to 80% in 2020.[34]
  - Treating all high-risk patients within catchment in the same way as local patients would be treated. This has sometimes been called a "just say yes" campaign where antenatal transfers are accepted by the tertiary maternity team without consultation with the NICU, unless the tertiary NICU or maternity unit are moving equivalent antenatal/postnatal patients from their own centre.
  - Development of standardised guidelines across the network for managing clinical scenarios frequently culminating in extreme preterm birth.
- Joined up working between LMSs/LMNSs and neonatal ODNs to review all exceptions to the designated antenatal and postnatal transfers pathways ensuring there is feedback to all clinicians regarding any learning outcomes. This was only happening in 40% networks in October 2019, but during deep-dive visits it was apparent that most networks have now got this system in place.
- Involvement of ambulance services to understand the requirements and implement changes to expedite moving mothers of high-risk infants.

[31] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data*

[32] *British Association of Perinatal Medicine Perinatal Management of Extreme Preterm Birth Before 27 weeks of Gestation (2019): A BAPM Framework for Practice, October 2019. Available at https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019*

[33] *Edwards K, Impey L. (2019) Extreme preterm birth in the right place: a quality improvement project Arch Dis Child Fetal Neonatal Ed*

[34] *Source: GIRFT Transport Questionnaire Nov 2019 and deep-dive visits*

IN PRACTICE

Pan-London guidance for in-utero transfer

London Maternity Clinical Network and London Neonatal ODN

As a response to the *Action on Mortality* quality improvement programme, the London Maternity Clinical Network and the London Neonatal ODN collaborated on the development of pan-London guidance for in utero transfer. A joint working party reviewed the existing evidence for in-utero transfer and predictive testing with a view to formalising the in-utero pathway and the processes which underpin it, thereby standardising and assisting in the clinical decision-making process.

The guidance, which builds upon the British Association for Perinatal Medicine (BAPM) 2008 document on the management of acute in utero transfers, aimed to improve the number of babies born at <27 weeks' gestation in a maternity service with a co-located NICU, improve the experience of parents transferred, decrease the time clinicians spend arranging an in-utero transfer and reduce the number of unnecessary transfers.

Following the publication of the guidance, the neonatal ODN continued to audit in-utero transfers. All failed in-utero transfers were reviewed. Despite a small improvement in the numbers of successful transfers, data stayed well below the required 85% of deliveries at <27 weeks needed to achieve the national ambition. Further review suggested this was due to a range of factors, including the identification of threatened preterm labour and the time taken to arrange the transfer. A service pilot commenced in September 2020 to deliver further improvements.

The pilot focused on women presenting with threatened pre-term labour and were less than 27 weeks pregnant. The pilot required the referring labour ward to contact Emergency Bed Service (EBS), who in the first instance contact the nearest in-network maternity service with a co-located NICU. The call is directed to the NICU and the nurse in charge takes down the details on a specifically designed transfer pro forma, contacts the labour ward and provides the details to enable a decision to be made to transfer or not following a discussion with the on-call consultant obstetrician. The NICU nurse confirms (or not) a decision to accept the transfer and the EBS facilitates the clinical handover and ambulance transfer.

During the pilot, there were a range of engagement activities between local multidisciplinary teams, the regional maternity team and the neonatal ODN, to iron out operational issues, share what was working well and learning when change was needed. Regional obstetric leadership was also available throughout to support local clinical decision-making and clarifying pathways – this was key to the success of the pilot

Early data from the pilot showed a significant improvement in the number of women transferred in-utero. For the small numbers of failed transfers during the pilot phase, exception reports were prepared and an implementation team comprising of clinicians from the maternity clinical and neonatal networks and from London Ambulance Service identified areas of learning to be considered by LMSs/LMNSs and Neonatal Clinical Oversight Groups.

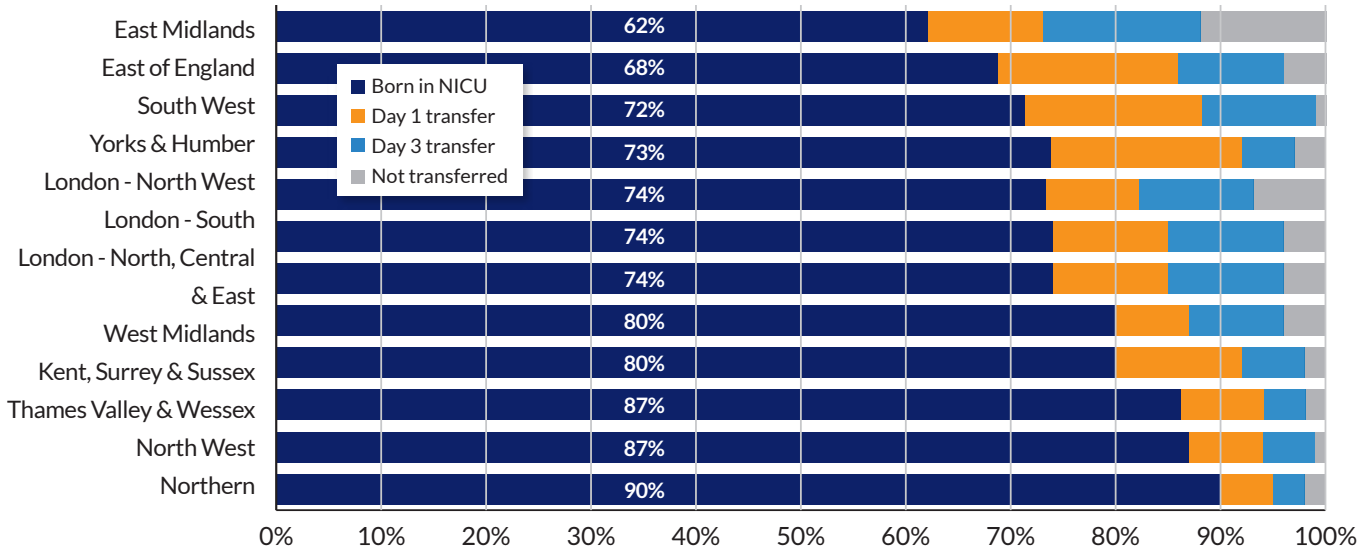
Standardised network-wide referral processes and guidelines for preterm antenatal transfer should be in place. Quality improvement resources are available to support increases in babies born in the right place as part of Maternity Neonatal Safety Improvement Programme and BAPM Antenatal Optimisation Quality Improvement Toolkit.[35, 36]

Of the high-risk infants born in LNUs, 88% (73-96%) were transferred by day one and 97% by day three, but this was variable across regions (**Figure 14**). Infants not transferred in the first week, including those that died in local units, ranged from 1-12%. Constrained network resource can be a significant impairment to network ability to improve adherence to patient pathways through monitoring. Some networks review data several times a week, providing early prompts to clinicians to ensure clinical discussions have occurred, exception reports are filed and the reasons for not transferring are clearly understood. Other networks are only able to retrospectively review data monthly or quarterly, which provides less complete information and does not provide the gentle nudges which help ensure best practice. Differences in ex-utero transfer also depend on the availability of transport services (discussed in the transport section of this report).

[35] *https://www.england.nhs.uk/mat-transformation/maternal-and-neonatal-safety-collaborative/*

[36] *https://www.bapm.org/pages/194-antenatal-optimisation-toolkit*

Figure 14: Proportion high-risk infants born in a NICU; transferred into a NICU by day 1, transferred into a NICU by day 3, and those not transferred in first week



Note: High-risk infants defined as singletons born before 27 weeks, multiples <28 weeks or birth weight <800g

Source: BadgerNet MY 2018/19

High-risk congenital anomaly pathway

GIRFT key findings:

- 17 of 22 neonatal surgical services are co-located with maternity services.
- A third of medical NICUs would plan to deliver a baby with gastroschisis in their unit.
- Deep-dive discussions suggested birth outside the surgically designated NICU was more likely to be considered acceptable if the surgical NICU was not co-located with maternity services.

There has rightly been a high level of focus on extremely preterm infants being born in a NICU, to reduce mortality and improve outcomes. Thus far, there has been less focus on whether infants with fetal congenital anomalies likely to require early surgical input are born in the network designated neonatal surgical centre (ideally co-located with the maternity centre) as recommended in national service specifications.[37] There are 22 neonatal surgical services, but only 17 of these have a co-terminus maternity centre, and some of the largest paediatric surgical services in children's hospitals (Great Ormond Street, Birmingham, Sheffield, Bristol, and Liverpool) require infants to be born in a nearby designated maternity service with fetal medicine expertise, and transferred in the early postnatal period. For babies requiring very early transfer to a different hospital, this can lead to separation of mother and baby. Every effort should be made to keep the mother and baby together and support family partnerships in care in these situations.

[37] *NHS England Paediatric Surgery: Neonatal Service Specification www.england.nhs.uk/wp-content/uploads/2013/06/e02-paedi-surg-neon.pdf*

It was clear from our clinical services questionnaires and discussion at deep dives that many babies with conditions requiring urgent surgical care would be planned to deliver in a medical rather than the designated surgical NICU or surgical maternity unit. One third of medical NICUs would plan delivery of a baby with gastroschisis or oesophageal/trachea-oesophageal fistula in their unit if the diagnosis was known antenatally.[38] Deep-dive discussions revealed this was much more likely to happen where the designated surgical maternity unit was not co-located with the surgical NICU and therefore the perceived benefit of being born in the surgical NICU was not so obvious. In contrast, no medical NICUs, LNUs or SCUs would plan delivery of a baby with Congenital Diaphragmatic Hernia in their unit, and this may be partly due to the clear pathway guidance produced by a BAPM Framework for Practise on this topic.[39]

From deep dive visits, it was apparent that clarity around cardiac network pathways varied. Clear antenatal planning regarding place of delivery, timing of transfer to the cardiac unit and the support required for emergent postnatal procedures e.g. septostomy, must be carefully considered.

It appears from this data that pathways for infants with high-risk surgical and cardiac conditions likely to require early transfer require clarification, with greater emphasis and understanding from all network hospitals and cardiac and surgical service providers of the importance of minimising mother-baby separation and avoiding early postnatal transfer. Failure to start care in the right place for these babies has an impact on neonatal transport services, quality of care for patients and their families and may also impact outcomes.

There is no current system in place to monitor whether these types of babies are born in the right place, in a similar fashion to the monitoring that occurs for the high-risk preterm infant. It is strongly recommended that neonatal ODNs, LMSs/LMNSs, Fetal Medicine Networks (FMNs) and surgical and cardiac subspecialities should start to review cases where an infant with a congenital anomaly requires an intensive care transfer from a unit that is **not** the designated surgical centre, to a surgical centre in the first 48 hours of life. Feedback should be given to all clinicians across the relevant specialities regarding any learning outcomes including potential to improve antenatal diagnoses.

Care pathways for other premature infants

GIRFT key findings:

- There is a negative correlation between LNU activity and likelihood of transfer for infants at 27- and 28-weeks' gestation.
- Transfer of preterm infants to NICUs in the first week of life is higher in low-volume LNUs than high-volume LNUs.
- Low-volume LNUs transferred 53% of babies at 27 weeks and 41% of babies at 28 weeks to NICUs in the first week of life.
- 51% of babies born in LNUs at 27 weeks receive three or more days of ventilation, reducing to 38% at 28 weeks and 21% at 29 weeks.
- Only 3% of low-volume LNUs meet the BAPM medical staffing requirements for separate tier 1 and 2 medical rotas during the week.

NHS England service specification pathway guidance says:

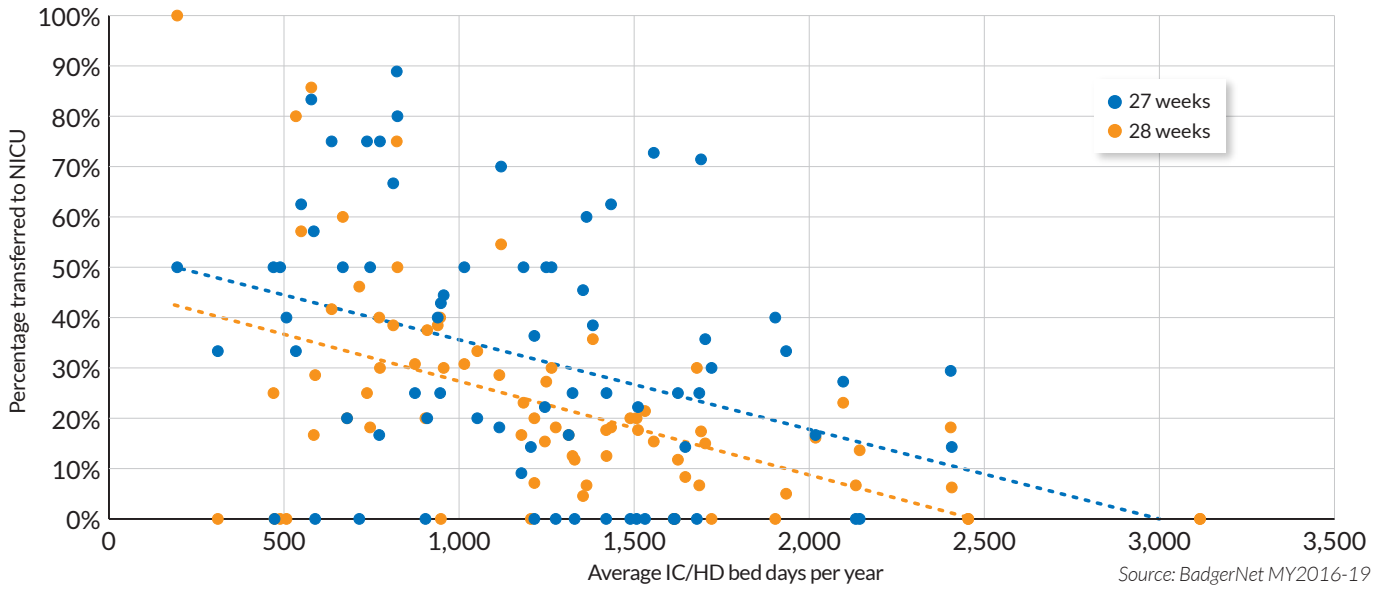
- LNUs can manage singletons born from 27 weeks, multiples from 28 weeks and babies weighing above 800g unless the baby requires intensive care for longer than 48 hours or needs specialist services not available in the LNU.
- SCUs can manage babies born from 32 weeks and with a birth weight greater than 1000g who are not likely to require short-term (48 hours) high-dependency care, with all babies requiring intensive care being moved to a NICU following stabilisation, and those requiring longer term high-dependency care moved to a NICU or LNU.
- Networks are allowed some flexibility around these pathways to provide the best fit for the regional population.

[38] *GIRFT Clinical Services Questionnaire December 2019*

[39] *BAPM (2018) National Care Principles for the Management of Congenital Diaphragmatic Hernia: A BAPM Framework for Practice https://www.bapm.org/resources/22-national-care-principles-for-the-management-of-congenital-diagphragmatic-hernia-2018*

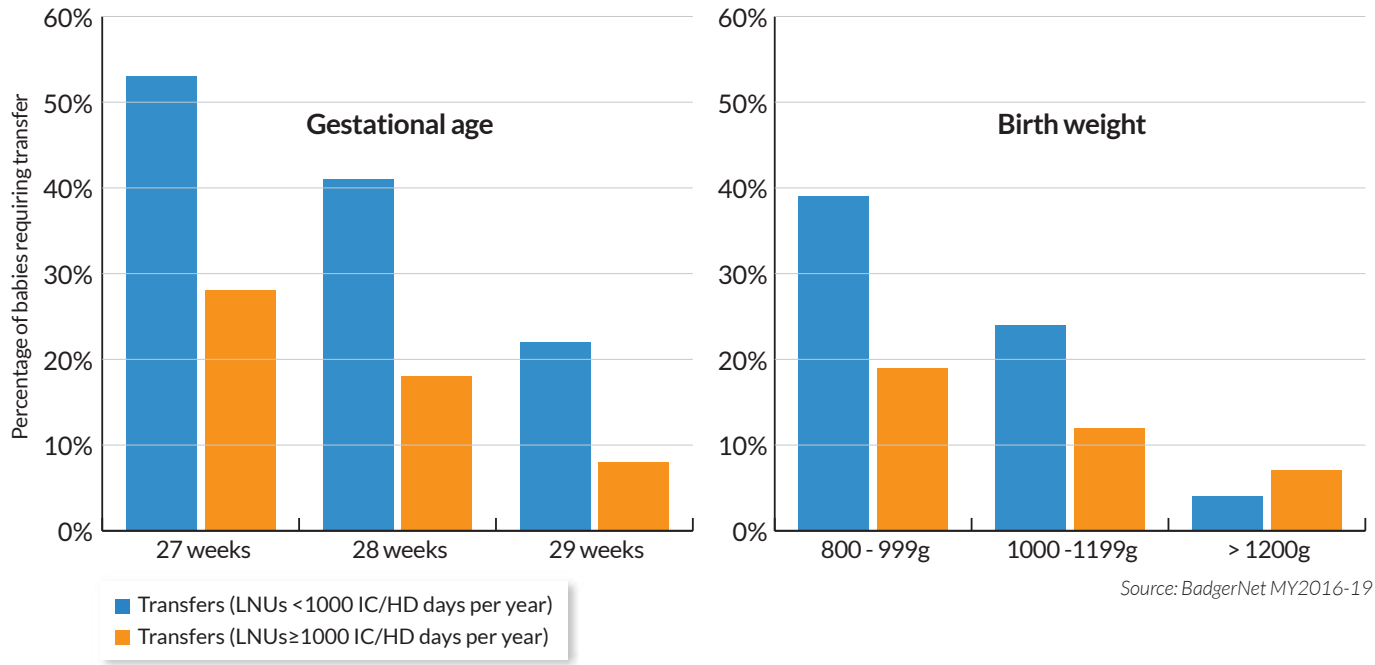
There are a high proportion of preterm infants born at 27 and 28 weeks and 800-1000g requiring transfer from a LNU to a NICU in the first week of life. Whilst some network pathways have been adjusted for 27 and/or 28-week infants in a very small number of LNUs during this period, this is not the case for the vast majority of units. There is a negative correlation between unit activity and likelihood of transfer for infants at 27- and 28-weeks' gestation and considerable variation is seen (**Figure 15**). Nationally, transfers are highest at 27 weeks (34%), (excluding those with birth weight <800g), and 800-999g (30%) (excluding those born before 27 weeks' gestation) but these rates are much higher in low-volume LNUs (53% at 27 weeks, 41% at 28 weeks and 39% at birth weight <1000g (excluding babies born <27 weeks)) (**Figure 16**).

Figure 15: Proportion infants born 27- and 28-weeks gestation in each LNU transferred to NICU in first week of life



Source: BadgerNet MY2016-19

Figure 16: Proportion of babies of different gestational ages and weights, requiring transfer from LNUs to NICUs in first week of life, for high volume LNUs and low volume LNUs



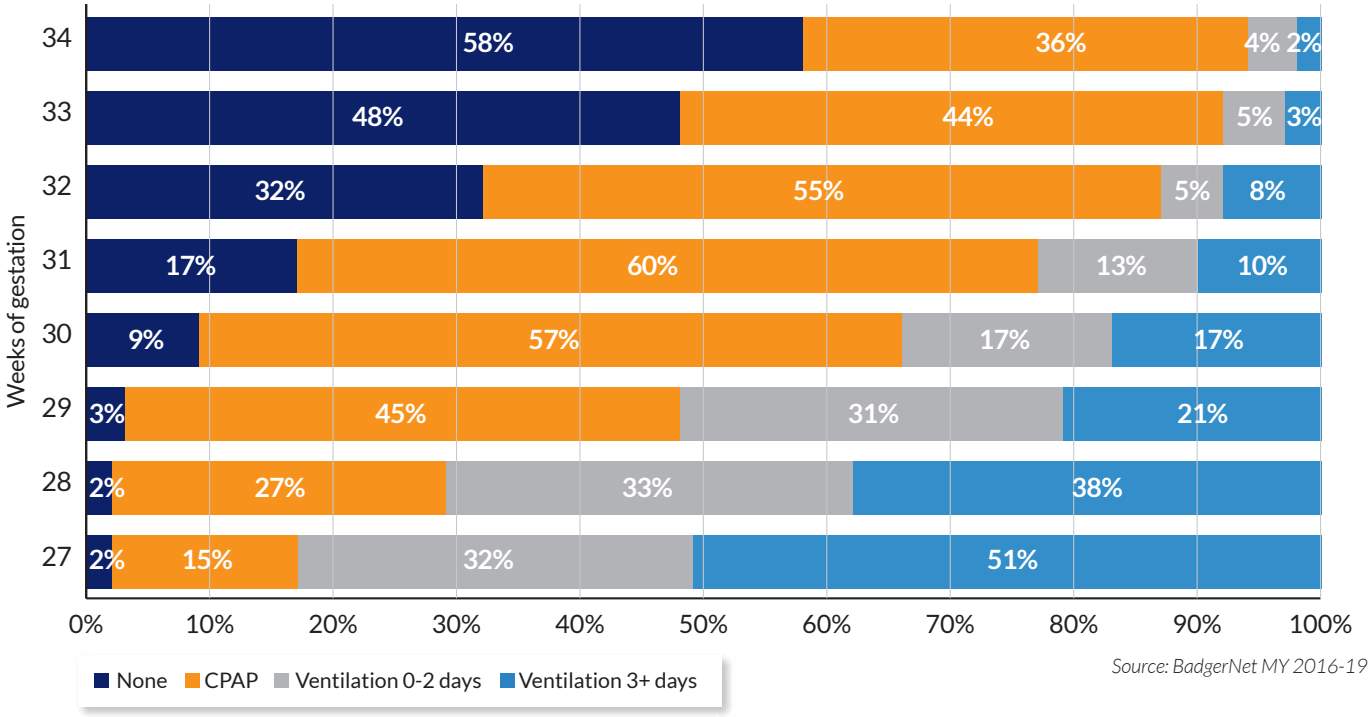
Source: BadgerNet MY2016-19

Notes: High volume is defined as ≥1000 IC/HD bed days/year and low volume is <1000 IC/HD bed days/year.
Babies with birth weight <800g are excluded from the gestational age analysis.

This is concerning because early uplift transfers for this group of premature infants are associated with increased mortality and severe brain injury, compared with birth in the NICU.[40, 41]

Respiratory requirements in the first week of life (**Figure 17**) show that at 27 weeks, 83% babies born in LNUs receive ventilation, of which 51% of babies will need three or more days of ventilation (an intensive care activity) which is above the suggested threshold for transfer to a NICU. This reduces to 38% at 28 weeks and 21% at 29 weeks.

Figure 17: Respiratory requirements in the first week of life for babies born in LNUs, from 27-34 weeks' gestation



Source: BadgerNet MY 2016-19

Babies needing ongoing intensive care, even for one to two days, need separate medical staff to the general paediatric services as outlined in BAPM standards.[42] The number of low-volume LNUs achieving this is very low (3% on weekdays, 7% at weekends - see GIRFT Neonatology Workforce report for more details) which may explain why transfers are so high for infants 27-28 weeks and also for babies <1000g.

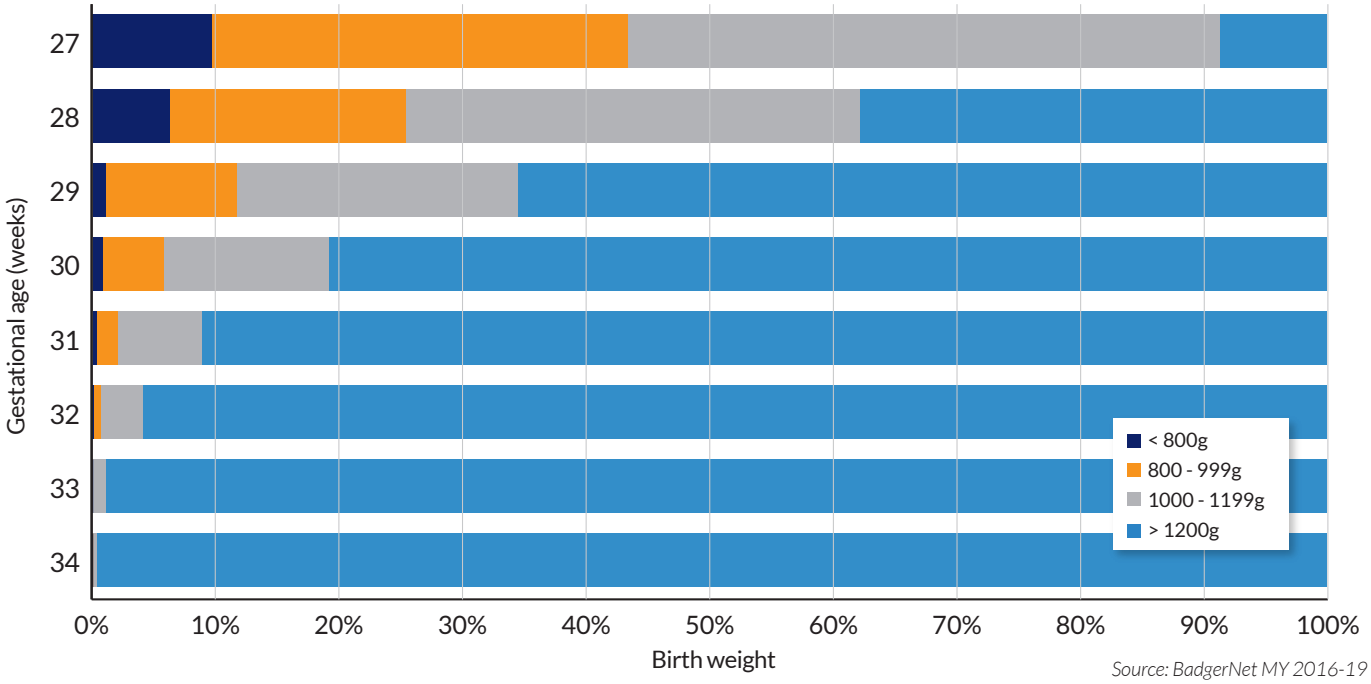
Figure 18 shows weight distribution of babies at different gestations, with 45% of babies at 27 weeks having a birth weight <1000g, dropping to 25% at 28 weeks and 12% by 29 weeks.

[40] *Helenius K, Longford N, Lehtonen L, Modi N, Gale C. (2019) Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching BMJ*

[41] *Redpath, S., Shah, P.S., Moore, G.P. et al. (2020) Do transport factors increase the risk of severe brain injury in outborn infants <33 weeks gestational age?. J Perinatol*

[42] *BAPM (2018) Optimal arrangements for Local Neonatal Units and Special Care Units in the UK https://www.bapm.org/resources/2-optimal-arrangements-for-local-neonatal-units-and-special-care-units-in-the-uk-2018*

Figure 18: Birth weight distribution for babies 27-34 weeks' gestation (MY2016-19)



Source: BadgerNet MY 2016-19

Outcomes for infants 27-31 weeks in England, comparing place of birth, are the subject of a current research study (the OPTI-prem study[43]), the results of which are eagerly awaited. However, the data above suggests that where capacity permits, networks should carefully consider adjusting thresholds for in-utero transfer in low-volume LNUs to <29 weeks' gestation and <1000g, to reduce known risks associated with transfer for this high-risk group pending any decisions regarding reconfiguration. High-volume LNUs that do not meet BAPM staffing standards for tier 1 and tier 2 rota separation (25% of high-volume LNUs) should expedite plans to accomplish this. If this is likely to take some time, consideration should be given to temporarily adopting the adjusted thresholds suggested for low-volume LNUs, network capacity permitting.

Pathways to reduce unnecessary mother and baby separation

GIRFT key findings:

- 5% of term babies were admitted to neonatal units in FY 2018/19 (ATAIN), with highest admissions in NICUs (5.9%).
- There is ongoing wide variation in ATAIN rates across neonatal services.
- There is wide variation in availability of neonatal community outreach services and support for short-term nasogastric tube feeding. This is most likely to be available in NICUs.
- Some outreach services cover a wider area than the local neonatal unit and are expanding the scope of their remit.

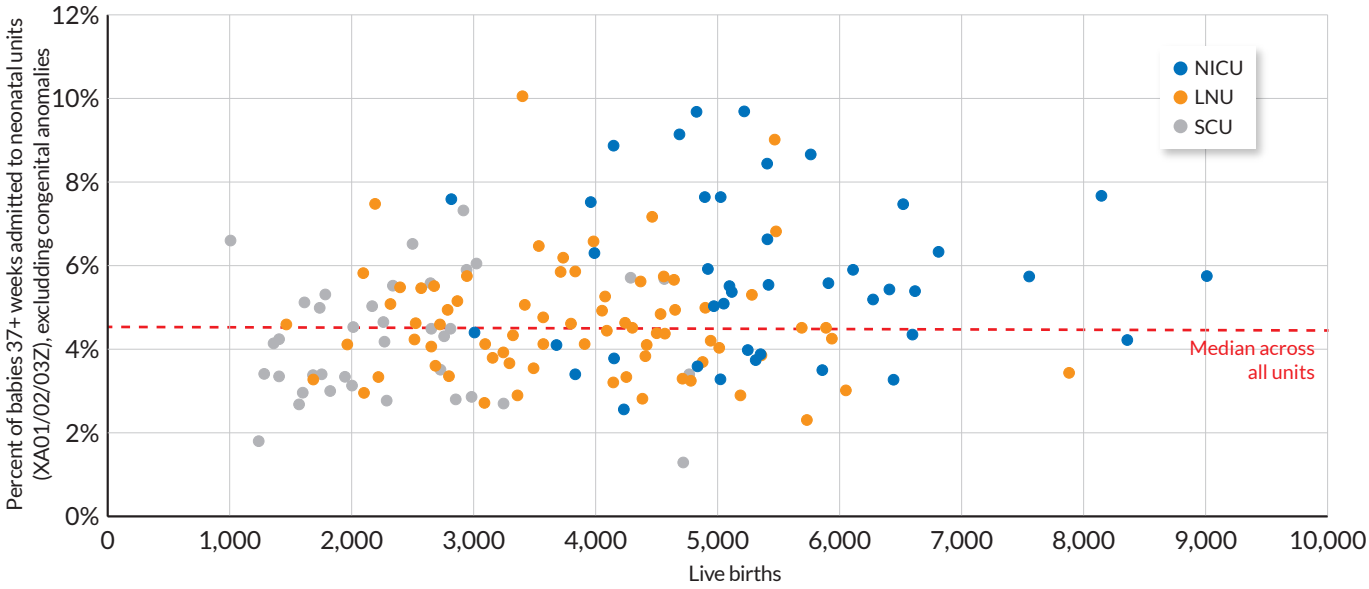
Avoiding unnecessary separation of mothers and babies has been the focus of much attention in the last few years, with all units responding to the NHS England quality improvement initiative *Avoiding Term Admissions to Neonatal units* (ATAIN programme).[44] The programme aims to reduce mother-baby separation by early preventative actions and improving transitional care arrangements. The 9% reduction in special care activity, compared with a 6% drop in term admissions since 2015 would strongly suggest this is the case although this may also be influenced by other factors including improvements to the pathway to home.

[43] *See https://clinicaltrials.gov/ct2/show/NCT02994849*

[44] *https://www.england.nhs.uk/mat-transformation/reducing-admission-of-full-term-babies-to-neonatal-units/*

The average percentage of term admissions (excluding those with known fetal anomalies) admitted to neonatal units is 5% overall (5.9% for NICUs, 4.6% LNUs and 4.2% SCUs) with an overall median 4.5%. (IQR 3.6-5.7%). The high level of variation between trusts suggests there is further work to be done in this area for some units (see **Figure 19**). Those units with above average percentage of term admissions should continue to work on strategies to reduce term admissions into neonatal units including development of transitional care in line with BAPM Framework,[45] and adherence to existing guidance (ATAIN) and Clinical Negligence Scheme for Trusts (CNST) requirements.

Figure 19: ATAIN results compared with live births for FY 2018/19



Source: BadgerNet FY2018/19, GIRFT Clinical Services Questionnaire, December 2019

Improving discharge pathways to home is also an important factor in reducing unnecessary family and baby separation. From the data packs and deep-dive visits we found there was significant variation in the neonatal community outreach support available following discharge. Overall, 57% of services had outreach services, but this was much higher in NICUs (84%), compared with LNUs (56%) and SCUs (27%). In addition, short-term nasogastric home tube feeding, which has been shown to reduce length of stay as well as having very positive feedback from parents,[46] is only currently available in 70% of NICUs, 40% of LNUs and 30% of SCUs.

During our deep-dive visits it was apparent that some services are expanding the range of support they can provide, including supporting home phototherapy services (see example) and intravenous antibiotics. One of the current impediments to developing neonatal outreach services is the lack of a clear payment structure. Some regional specialised commissioning groups have supported funding for these services, with extension of services across a wider region rather than just the local hospital service. Neonatal outreach services, including the ability to support short-term nasogastric tube feeding for preterm infants and access to allied health professional (AHP) services for infants with complex needs, should be consistently supported across all networks. It is hoped that the new payment system will make this easier, allowing more flexibility for expansion of these services to support earlier discharge, improving care and experiences for families as well as reducing costs through reduced length of hospital stay.

[46] *Bissell G., Wood A., Peak S., et al. (2009) Changing practice by the earlier introduction of tube feeding at home. Infant https://www.infantjournal.co.uk/pdf/inf_029_fee.pdf*

IN PRACTICE

Neonatal community outreach including home phototherapy service

University Hospitals Birmingham NHS Foundation Trust

The Neonatal Community Outreach Team (NCOT) for Birmingham and Solihull United Maternity and Newborn Partnership (BUMP) is hosted by University Hospitals Birmingham NHS Foundation Trust (UHB), for babies from the Birmingham Heartlands Hospital (BHH), Good Hope Hospital (GHH) and Birmingham Women's Hospital (BWH).

The NCOT was established in 2010 as part of the neonatal community outreach CQUIN as there was strong evidence that early supported discharge would optimise the use of special care cots with better consequential utilisation of ITU and HDU cots

Initially the NCOT team covered just BHH and GHH Monday to Friday 8am-4pm, however the service was expanded in 2019 to cover BWH with extended hours. The team now work 7 days a week, 8am-6pm weekdays and 9am-5pm on weekends and bank holidays. The team has the equivalent of 10 WTE staff, one Band 7 lead nurse, four Band 6 nurses, four Band 5 nurses and one Band 3 admin support, with all team members working cross-site.

NCOT inclusion criteria are:

- Gestation, at least 34+1 weeks corrected gestational age (CGA) and less than 35 weeks CGA.
- Weight, at least 1.6 kg and less than 1.8kg.
- Nasogastric tube feeding (short term).
- Sluggish weight gain or to support babies who are close to losing 10% of their birth weight to prevent readmission.
- Oxygen dependent babies on up to 0.5L/min of nasal prong oxygen.
- Neonatal abstinence syndrome (NAS) (weaning well, on medication, babies going to foster/adoptive care or mother and baby unit only).
- Babies with continuing short-term nursing/medical needs (support for families i.e. undiagnosed conditions or surgical care).
- Palliative care when parent chooses to take their baby out of the hospital setting.
- Palivizumab clinics and baby groups.

In 2019, the home phototherapy service was launched enabling eligible jaundiced babies to be treated at home with daily input from the NCOT nurses. These babies are referred directly from the community to prevent readmission to a hospital or can be discharged from the neonatal unit or postnatal wards.

The NCOT BUMP team had 475 babies under their caseload last financial year with 188 babies under home phototherapy decreasing the special care occupancy of BHH from 80% to 64%. The NCOT team continued to be operational during COVID-19 pressures (including seeing covid-positive families), supporting the babies and their families with very positive parental feedback.

Pathways to other paediatric services

GIRFT key findings:

In the three-year period FY2016-19 there were:

- 2,267 babies being cared for in neonatal units beyond 44 weeks PMA receiving 10,845 bed days of care, of which 44% were receiving IC/HD care
- 618 babies were being cared for in neonatal units beyond 48 weeks, 246 requiring IC/HD care and 372 babies requiring SC.

Babies who have reached 44 weeks' postmenstrual age (PMA) are no longer considered to be neonates and should be appropriately transitioned to children's services if they have ongoing care needs. Whilst it is appropriate to continue to support some infants beyond the 44-week cut-off, our data (see key findings), and information from deep-dive visits suggests that there are difficulties transitioning to paediatric specialist services or paediatric critical care due to bed shortages. Shortage of space in paediatric critical care is well recognised (see GIRFT's Paediatric Critical Care Report) and has a knock-on impact on neonatal intensive care capacity. Any re-modelling for additional paediatric critical care capacity should include these patients.

Network pathways: conclusions

There is room for further improvements to be made to optimise antenatal and postnatal network pathways, for both preterm infants and older infants with congenital anomalies requiring early surgical or cardiac intervention. Additional data regarding transfers of infants from LNUs at 27-29 weeks' gestation is provided with recommendations to modify pathways for some LNU services. Reducing mother and baby separation remains a priority for both the high-risk infant, and for the high number of term and near-term infants who require care from neonatal and maternity services. Further reductions in the proportion of term babies admitted to neonatal units are possible with increased development of transitional care services and ongoing use of the ATAIN programme. In addition, neonatal outreach services need to be consistently available across all areas of the country and the remit of these services can then be expanded further to reduce in-hospital stay and improve family experience.

Recommendations to strengthen networks and improve patient pathways

Recommendation	Actions	Owners	Timescale from date of publication
1. Improve neonatal ODN effectiveness through development of a more consistent and equitable funding model, and strengthen relationships with key stakeholders.	**a** Develop an agreed requirement for national core network funding (relative to network activity) to ensure all networks have sufficient and equitable resource to be able to operate effectively across all areas of their remit. Arrangements must be futureproofed for changes to funding models and the move to ICSs. A national neonatal ODN service specification is needed which reflects these core funding requirements.	National & regional NHS specialised commissioning teams and Neonatal CRG	12 months
	b Put arrangements in place to allow for substantive appointments to network posts.	NHS regional specialised commissioning teams, network hosts	3 – 6 months
	c Strengthen commissioning relationships with neonatal ODNs. Strong commissioning leadership must be present to develop the business case for service change and subsequently support any reconfiguration / re-designation of services.	NHS regional specialised commissioning teams and neonatal ODNs	2 years
	d Ensure parents play an integral part in all aspects of network activity including representation on the network board.	Neonatal ODNs	6 – 12 months
	e Share ownership and joint working where neonatal ODN and LMS/LMNS work plans align. Planning guidance to LMS/LMNS for 2021/22 makes it clear that they must take responsibility for working with neonatal ODNs on implementing the findings of the NCCR.	Neonatal ODNs and LMSs/LMNSs	Immediate and Ongoing
	f Develop closer relationships with paediatric clinical networks, embedding paediatric sub-specialty input into antenatal and postnatal pathways within networks.	Neonatal ODNs, paediatric sub-speciality networks	1 – 2 years

Recommendation	Actions	Owners	Timescale from date of publication
1. (Continued)	**g** Strengthen neonatal ODN relationships with LMSs/LMNSs and Fetal Medicine Networks (FMNs). The footprints for these organisations should be aligned as much as possible together with a similar collective ICS footprint. An overarching regional high risk perinatal group allows streamlining of joint maternity and neonatology objectives.	ICSs and regional specialised commissioning teams to lead	1 – 2 years
2. Regional neonatal transport services must meet national service specification standards and the requirements of neonatal ODNs.	**a** Ensure network risk registers include service specification response times and capacity benchmarks when they are consistently not met. Include current mitigations and an action plan. Urgent action is required where there is major disruption to patient flow.	Neonatal ODNs, Transport service providers	6 – 12 months
	b Confirm funding for transport services including ambulance provision, particularly where these services are integrated with NICUs. Capital funding for equipment should be included within funding allocations; charitable funding should not be the primary funding source.	Transport service providers, neonatal ODNs	1 – 2 years
	c Ensure consultant (tier 3) staff are always available 24/7 to perform transfers if clinically required. Where this is not currently possible, this issue should be on the trust and network risk register and include current mitigations and an action plan.	Transport service providers, neonatal ODNs, NHS regional specialised commissioning teams	1 – 2 years
	d Analyse the likely impact of changes to network pathways or configuration on transport service capacity and responsiveness.	Neonatal ODNs	Immediate and ongoing
3. Significant investment in additional cots is required to implement optimal care pathways as recommended in the Neonatal Critical Care Review (NCCR).	**a** Clarify the amount of capital funding available in the NHS Long Term Plan for additional cot capacity. Any critical gaps with no identified funding commitment will need to be escalated through regional specialised commissioning teams and ICSs for national review.	NIB, MTP, NHS National specialised commissioning team alongside regional specialised commissioning teams and ICSs	For immediate mitigation, 6 –12 months with definitive resourcing established in 2 – 5 years
	b Clarify how the capital funding model within NHS England is changing and how additional cots will be funded as the neonatal intensive care footprint is larger than the ICSs.	National specialised commissioning team and ICSs	3 – 6 months
	c Where neonatal ODNs and regional teams identify a clear need for increased capacity within a trust, there must be an action plan for implementation including current mitigations and escalation plans if difficulties are encountered.	Trusts, neonatal ODNs and NHS regional specialised commissioning teams, ICSs	6 – 12 months

Recommendation	Actions	Owners	Timescale from date of publication
4. Optimise antenatal and postnatal patient pathways and reduce unnecessary mother-baby separation.	**a** Ensure all network hospitals and cardiac and surgical service providers understand the importance of minimising mother baby separation and avoiding early postnatal transfer. Clarification of birthing hospital for high-risk surgical and cardiac conditions likely to require transfer in first 48 hours of life will help to address this.	Neonatal ODNs and transport services	3 – 6 months
	b Commit to joined up working between LMSs/LMNS, FMNs, neonatal ODNs, transport service providers and paediatric subspecialties to review all exceptions to the preterm designated antenatal and postnatal transfer pathways as well as for babies with congenital anomalies requiring urgent surgery. Feedback should be given to all clinicians across the relevant specialities regarding any learning outcomes including potential to improve antenatal diagnoses. For congenital anomalies, exception reporting and review is recommended for any infant requiring an intensive care transfer from a unit that is not the designated surgical birthing centre, to a surgical centre in the first 48 hours of life.	LMSs/LMNSs, FMNs, neonatal ODNs, paediatric sub-specialty ODNs and transport service providers	2 – 5 years
	c Consider, where capacity permits, adjusting gestational age for in-utero transfers in low volume LNUs (<1,000 IC/HD per year) to under 29 weeks gestation and under 1,000g, to reduce known risks associated with transfer for this high-risk group pending any decisions regarding re-designation.	Neonatal ODNs, NHS Specialised Commissioning	Immediate and ongoing
	d Expedite plans for high-volume LNUs that do not meet BAPM staffing standards for Tier 1 and 2 rota separation to meet these standards. If it is likely to take some time, consideration should be given to temporarily adopting the adjusted thresholds suggested for low volume LNUs, network capacity permitting.	Trusts, neonatal ODNs	Immediate and ongoing
	e 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 AHP services. This may require network and commissioning involvement to develop services across the footprint of the network.	Trusts, neonatal ODNs and NHS regional specialised commissioning teams	2 – 5 years
	f Consider maternity unit size, and projected changes to maternity activity alongside socioeconomic factors when evaluating whether an LNU or a SCU is more appropriate for the local population.	Neonatal ODNs and LMSs/LMNSs	Immediate and ongoing
	g Continue to work on strategies to reduce term admissions into neonatal units, particularly units with above average term admissions, including development of transitional care in line with BAPM Framework, and adherence to existing guidance (ATAIN) and CNST requirements.	LMSs/LMNSs and Trusts	Immediate action

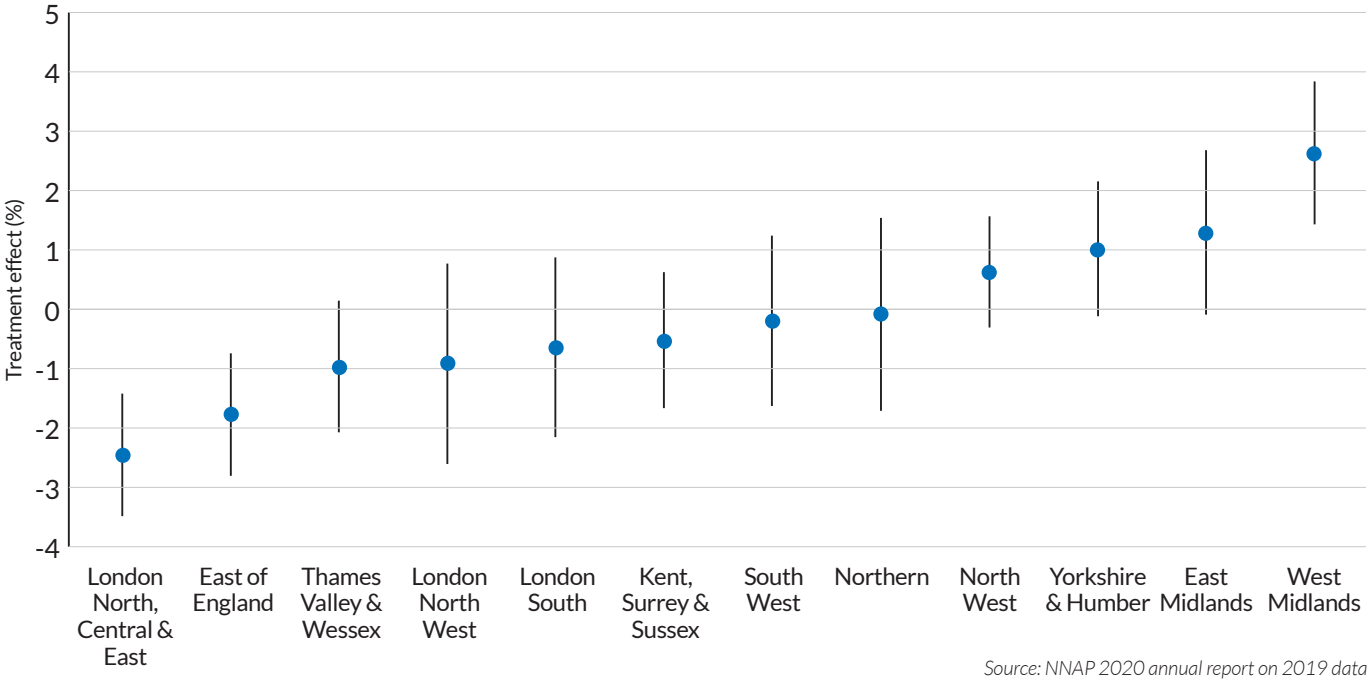
Improving clinical aspects of care

Half of all neonatal deaths occur in babies aged less than 28 weeks.[47, 48] We also know from serial data collection through the National Neonatal Audit Programme (NNAP)[49] that there is ongoing significant variation in key morbidity and mortality outcome measures across neonatal operational delivery networks (ODNs) in preterm infants including:

- Necrotising enterocolitis, which varied between 3.6% and 9% of babies admitted at <32 weeks in 2019.
- Bronchopulmonary dysplasia (BPD) or death, which varied from 32-42% of babies admitted at <32 weeks (2017-19).
- Mortality, which varied between 9.5% and 21%, for babies admitted at <28 weeks, (MY2016-19).

For BPD and mortality, case mix adjustment has been performed to estimate the size of "treatment effect" by network. This adjustment compares the rate of BPD or mortality in a network relative to the rate seen in a matched sample of babies in all units. A positive treatment effect means the rate in a network is higher than that seen for comparable groups of babies in all units. The data suggests there is wide variation in treatment effects across networks, shown in **Figure 20** (mortality) and **Figure 21** (rates of BPD or mortality).

Figure 20: Treatment effect on rates of mortality in very preterm infants (<32 weeks' gestational age), by neonatal network (July 2016-June 2019)



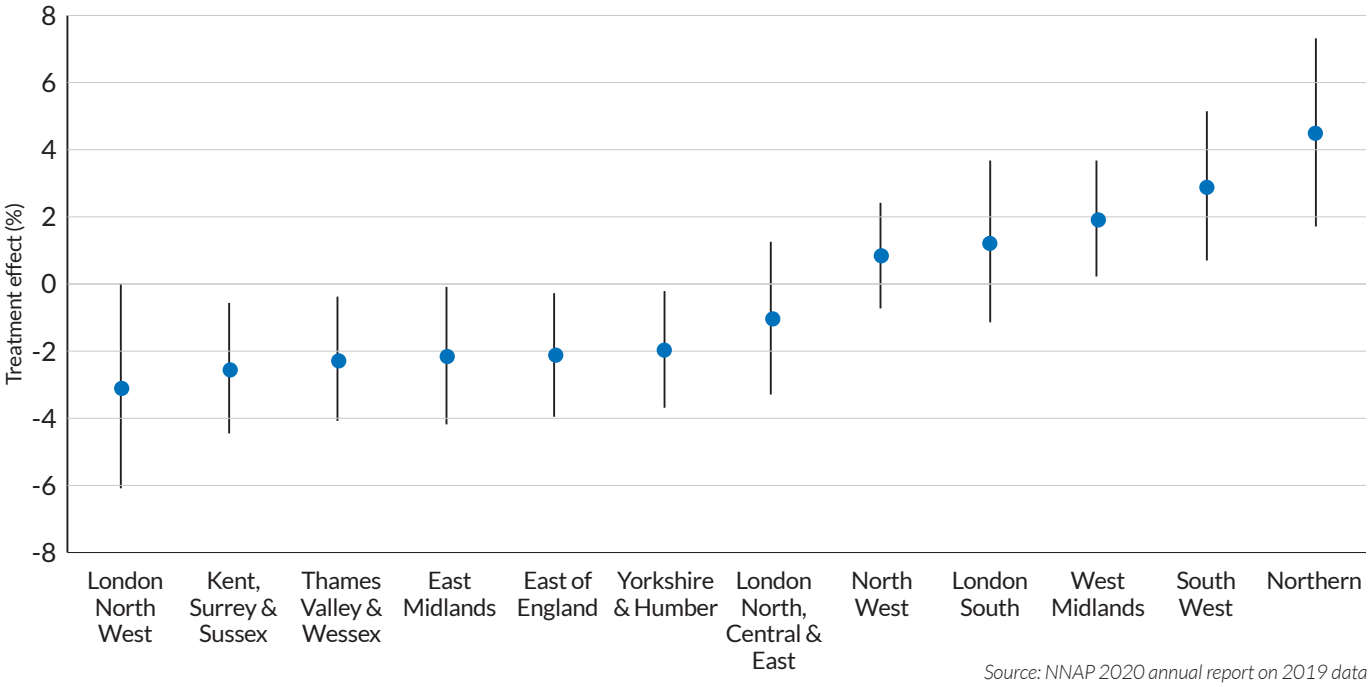
Source: NNAP 2020 annual report on 2019 data

[47] *ONS (2019) Child and infant mortality in England and Wales: 2019. Stillbirths, infant and childhood deaths occurring annually in England and Wales, and associated risk factors www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2019*

[48] *MBRRACE-UK Perinatal Mortality Surveillance Report for births in 2019, https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_final.pdf*

[49] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data*

Figure 21: Treatment effect on rates of significant BPD or death in very preterm infants <32 weeks gestation, by neonatal network (July 2017-June 2019)



Source: NNAP 2020 annual report on 2019 data

We have focused on the following key factors that impact preterm babies' outcomes: providing the best start to life; optimising respiratory care; and improving access to breast milk. Improvements in all these measures will significantly impact mortality, neurodevelopmental outcome, necrotising enterocolitis, infection, chronic lung disease and other long-term health outcomes. Many of these are already a focus for quality improvement at local and national level.

In addition, we provide information on two areas that are less of a focus for neonatal services currently: neonatal haematology practices; and neonatal radiology support including pathways for babies presenting with bile-stained vomiting.

Preterm infants

Optimal start for preterm infants

GIRFT key findings:

- The median percentage of babies born at <30 weeks' gestation achieving antenatal steroids AND MgSO4 AND normothermia was just 40% (IQR 28-50%) in MY2018/19.
- Only 62% of units would aim to delay cord clamping for at least 60 seconds in babies of all gestations and provisional Q3 2020 NNAP data suggests only 35% of units delayed cord clamping for babies <32 weeks.
- There is a five-fold difference across networks in the proportion of babies born <27 weeks receiving cardiac compressions or adrenaline at birth (2016-19).

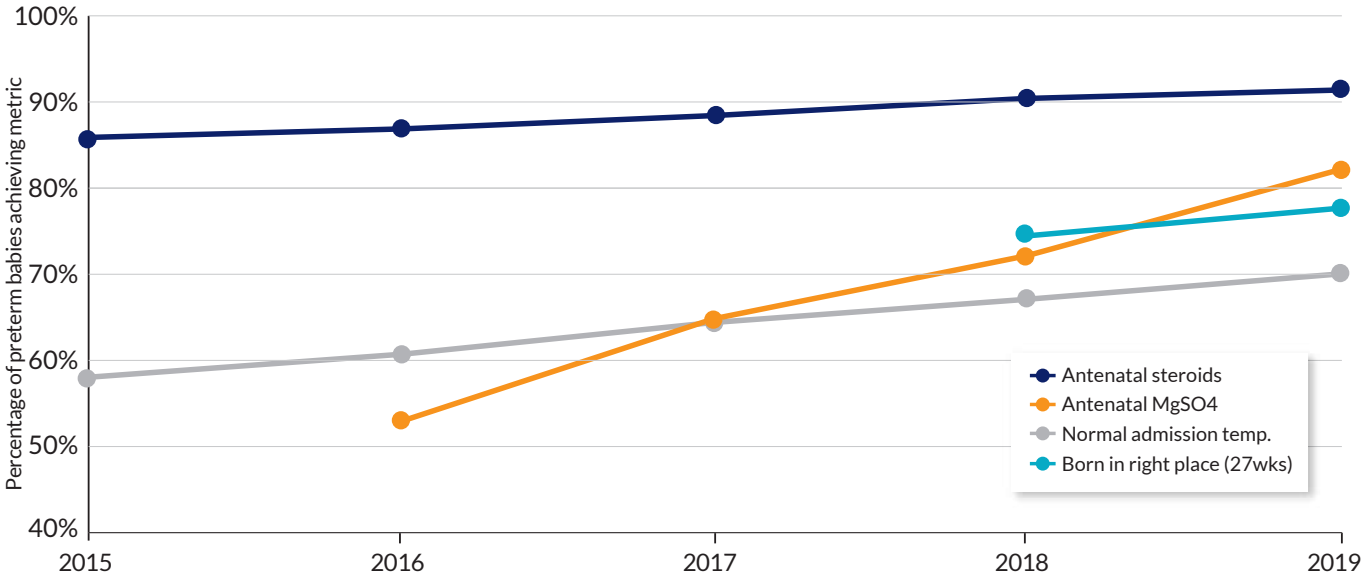
Antenatal factors and early thermal care

There are a range of antenatal and early postnatal measures associated with mortality, brain injury and necrotising enterocolitis in premature babies. High-risk preterm babies being born in a neonatal intensive care unit (NICU), rather than a local neonatal unit (LNU) or special care unit (SCU), is a key factor in improving outcomes. Babies born outside the NICU have a two- to three-fold increase in the risk of brain injury and 1.3 times the risk of death.[50] It is also important to ensure a co-ordinated approach across neonatology and maternity towards decision-making and counselling for women who are expected to deliver at the limits of viability using the BAPM Framework.[51] This measure is discussed in detail in the network pathways section of this report.

Other key measures include administration of antenatal steroids, magnesium sulphate (MgSO4) and maintaining normothermia from birth measured on admission to the neonatal unit.

These measures have been subject to data collection over several years through the NNAP[52] and there is year on year improvement in overall attainment of these key variables across the UK, shown in **Figure 22**. It is noticeable that the uptake of antenatal magnesium sulphate was rapid, and this was supported by a specific quality improvement programme, PReCePT,[53] which was funded for rollout across all units in England following a successful pilot in South West Academic Health Science Network (AHSN).

Figure 22: Percentage of preterm babies in UK achieving each of four set optimal start metrics



Source: NNAP

For our deep-dive visits, this data was split by gestational age to help individual trusts understand which areas required targeted improvement. The proportion of units achieving all three metrics (antenatal steroids, MgSO4 and normothermia on admission to neonatal) was also reviewed using three-year rolling averages There has been progress in achieving these measures across all unit designations in the last few years (**Figure 23**), but despite ongoing QI work in many trusts there is considerable room for progress across nearly all units with only 40% units achieving this in MY2018/19.

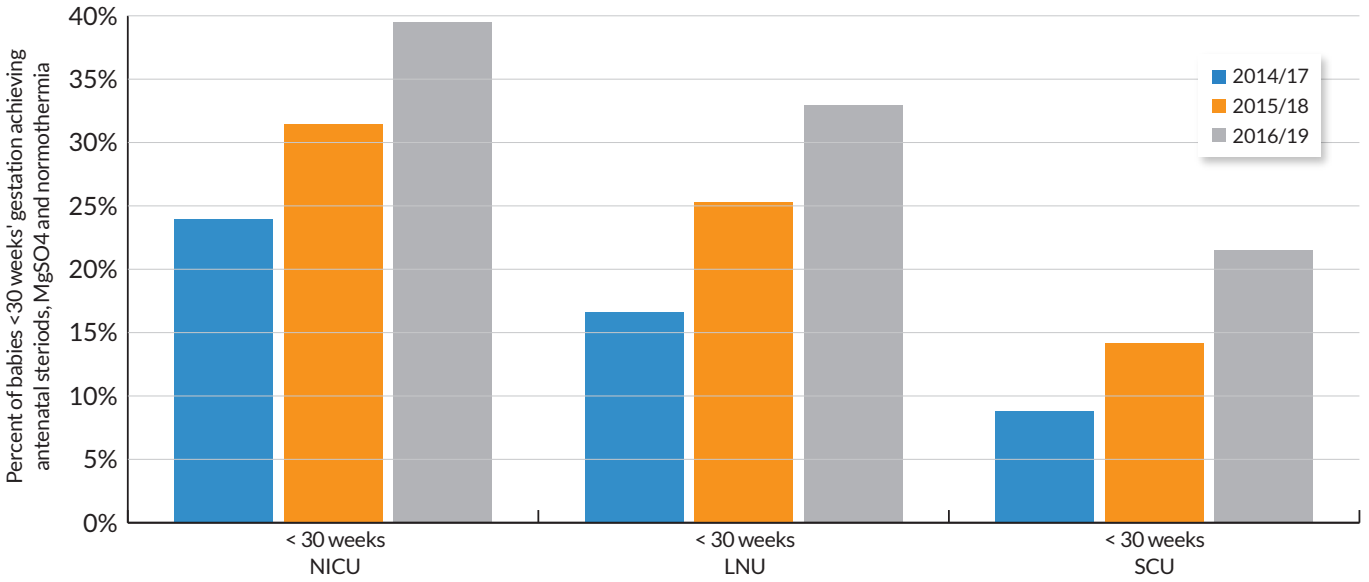
[50] *BAPM (2020) Antenatal Optimisation Toolkit https://www.bapm.org/pages/194-antenatal-optimisation-toolkit*

[51] *British Association of Perinatal Medicine Perinatal Management of Extreme Preterm Birth Before 27 weeks of Gestation (2019): A BAPM Framework for Practice, October 2019. Available at https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019*

[52] *https://nnap.rcpch.ac.uk/*

[53] *PReCePT (Preventing cerebral palsy in preterm babies) www.ahsnnetwork.com/about-academic-health-science-networks/national-programmes-priorities/precept*

Figure 23: Three-year rolling average for percentage of babies achieving antenatal steroids and MgSO4 and normothermia (MY2014-19)



Source: BadgerNet MY2014-19

Optimal cord management

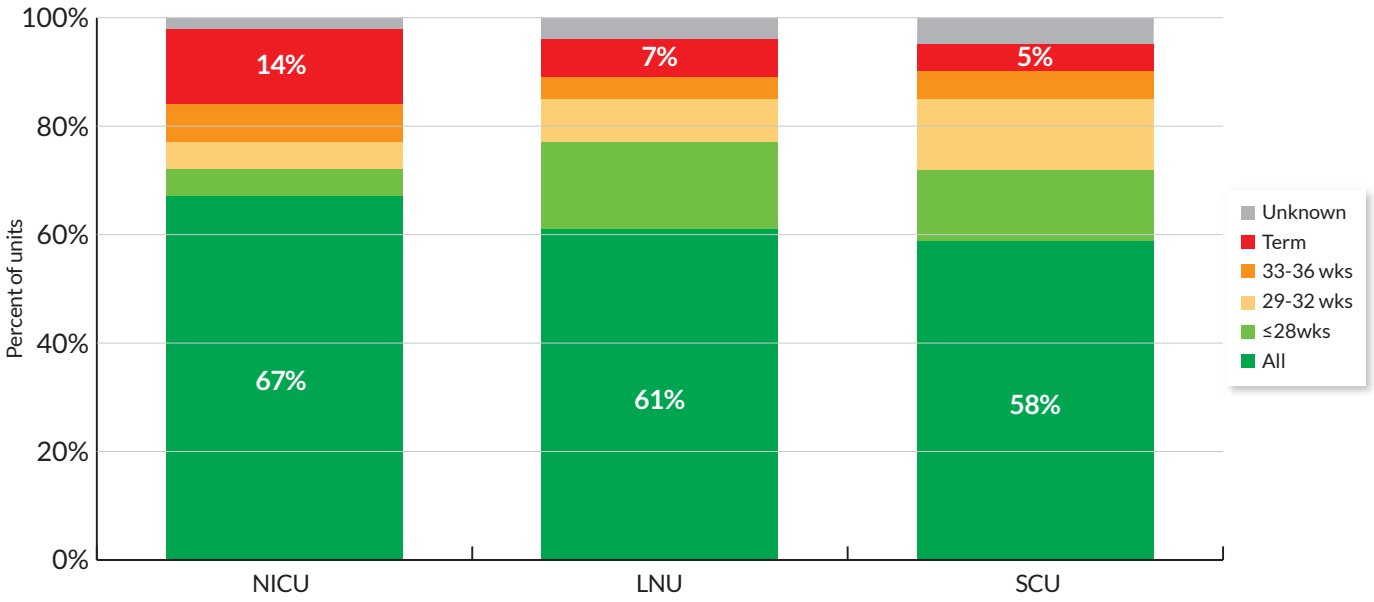
Optimal cord management (OCM - waiting at least 60 seconds after delivery before clamping the umbilical cord) results in a 28% reduction in mortality in babies <32 weeks.[54, 55] This is consistent with NICE guidance[56] and has recently started to be measured by the National Neonatal Audit Programme (NNAP). Data will be available for benchmarking in the 2021 NNAP report. GIRFT asked neonatal units at what age they would perform optimal cord management. In December 2019, only 62% of units would routinely wait 60 seconds before clamping the umbilical cord for babies at all gestational ages (the highest rates were seen in NICUs), with many units only doing this for infants at higher gestational ages (**Figure 24**). Provisional data for NNAP up to the end of Q3 2020 suggests 35% of babies <32 weeks' gestational age had at least 60 seconds delay before cord clamping which suggests there is significant room for improvement.

[54] *Fogarty M, Osborn DA, Askie L, et al. (2018) Delayed vs early umbilical cord clamping for preterm infants: a systematic review and meta-analysis. Am J Obstet Gynecol*

[55] *Rabe H, Gyte GM, Díaz-Rossello JL, et al. (2019) Effect of timing of umbilical cord clamping and other strategies to influence placental transfusion at preterm birth on maternal and infant outcomes. Cochrane Database Syst Rev*

[56] *NICE recommends waiting at least 30 seconds, but no longer than 3 minutes, before clamping the cord of preterm babies if the mother and baby are stable; NICE (2015) NG25 Preterm labour and birth*

Figure 24: Gestational age at which NICUs, LNUs and SCUs would perform optimal cord management



Note: 'Term' babies are defined as 37 weeks gestation or more. 'All' refers to babies of all gestations.

Source: GIRFT Clinical Services Questionnaire, November 2019

Some units and networks have started to look at the impact of achieving a larger core set of optimal start interventions for individual babies to focus on quality of care for individuals, rather than looking at these measures in isolation.

IN PRACTICE

The Big 5

Yorkshire and Humber ODN

The team at Yorkshire and Humber ODN (Y&H) set out to determine whether individual low-gestation babies (<32 weeks) receive five core early-care interventions and use this data to provide a focus for QI. These 'Big 5' interventions are:

- Delivery in appropriate location for gestational age;
- Antenatal steroids;
- Antenatal magnesium sulphate;
- Optimal cord management (OCM); and
- Normothermia on admission.

Retrospective data was collated by the ODN at unit and network level to review the number of babies receiving 100% provision of the Big 5. The initial phase of the project was to determine what the baseline for provision was.

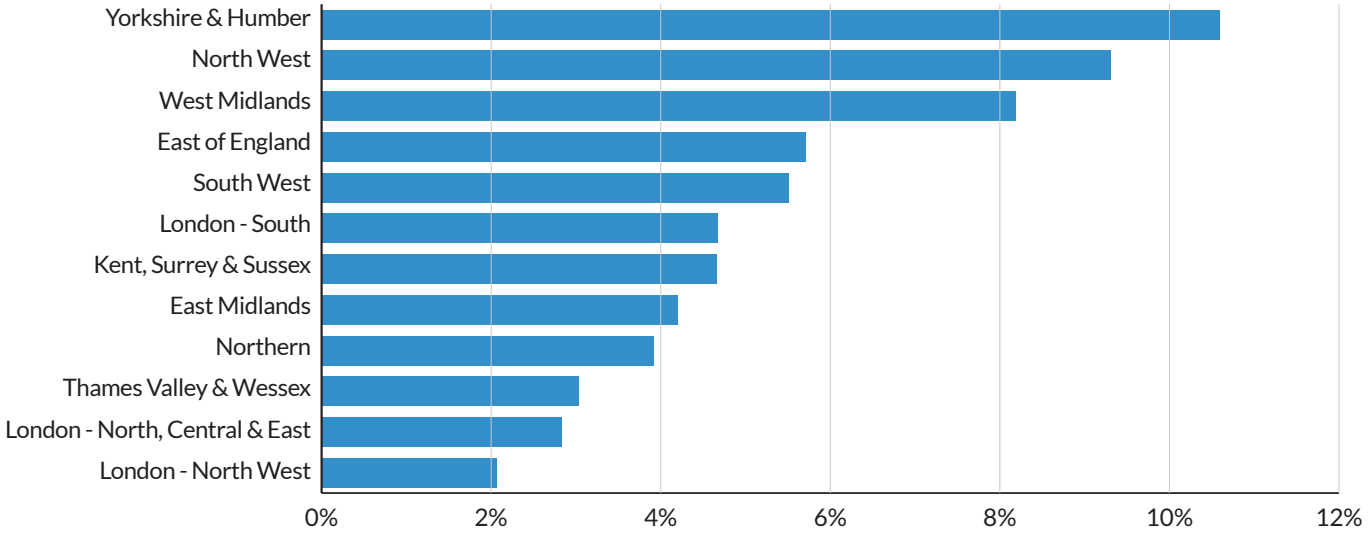
The main change that this project has brought about is the focus on quality of care for the baby rather than the individual elements of care. This has contributed to improved review and discussion between maternity and neonatal services as well as identifying key areas where specific interventions may be being missed. Across the network, OCM is the biggest factor for not achieving 100% provision for each baby.

Recent developments by BAPM and MatNeoSIP mean Y&H will be adding two further elements to their reviews (intrapartum antibiotics and early receipt of mother's milk), whilst also updating the antenatal steroids criteria with specific detail around receipt of a full course and within seven days of birth. 2020/21 data will soon be compared with 2019/20 data to assess the impact of change over 24 months and highlight specific areas for further concentrated QI.

Advanced resuscitation

There is variation across regions in the percentage of babies receiving cardiac compressions and/or adrenaline in the delivery suite. Most preterm babies require stabilisation rather than true resuscitation, and the small proportion receiving these more significant resuscitation measures have an increased risk of poorer outcomes including death and severe intraventricular haemorrhage (IVH).[57] Our data suggests a five-fold difference across networks in the proportion of babies <27 weeks receiving cardiac compressions or adrenaline over a three-year period (2016-19), shown in **Figure 25**, with higher rates in LNUs and SCUs (10-12%) than NICUs (3.3%) although the range of results was wide for all unit designations. The proportion fell to 3.3% across all units for babies at 27-30 weeks (range 1.8-4.3%). Differences in resuscitation rates for babies <27 weeks in LNUs and SCUs may relate to the less planned nature of the delivery as, where time is available, these mothers would be transferred in utero, and this may account for the differences seen. Further review of all extreme preterm infants <27 weeks who receive adrenaline and/or cardiac compressions at birth would help to improve understanding of potential modifiable factors.

Figure 25: Proportion of babies < 27 weeks receiving cardiac compressions or adrenaline at birth (MY2016/19)



Source: BadgerNet

Other early factors which may impact optimal start, including early access to maternal breast milk and early ventilator management, are discussed below.

Optimal respiratory care for preterm infants

GIRFT key findings:

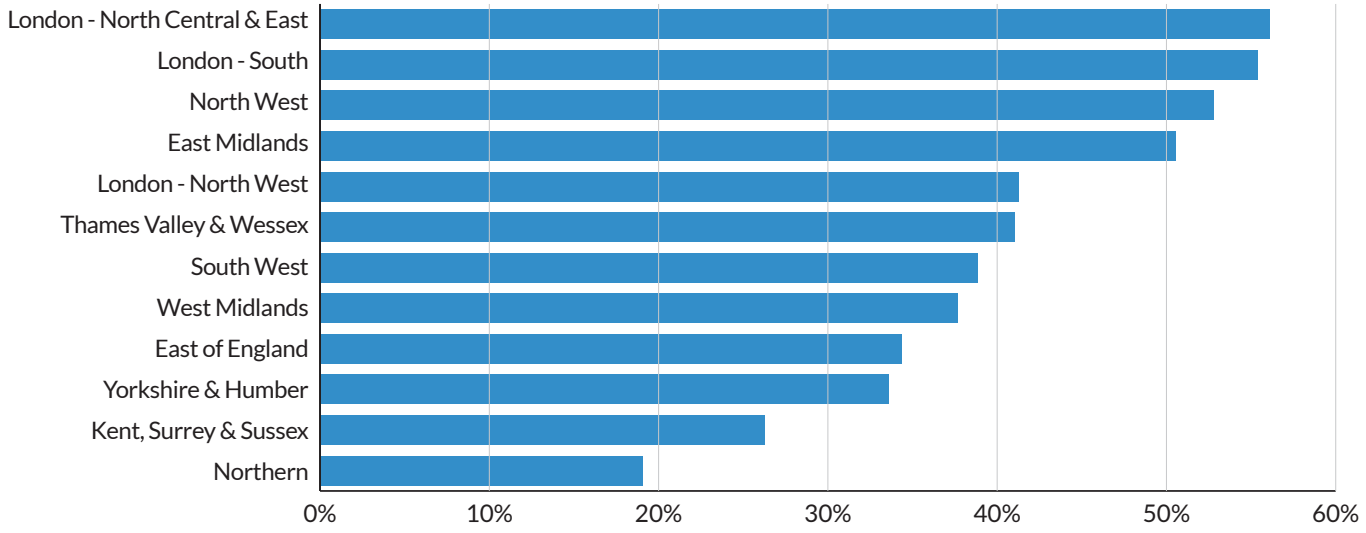
- There is wide variation across networks and trusts in the percentage of infants who are intubated and ventilated in delivery suite.
- Only one third of NICUs are routinely using LISA to administer surfactant (December 2019).
- 63% of units (86% NICUs, 67% LNUs and 32% SCUs) were using synchronised volume-targeted ventilation as their primary ventilation mode (December 2019).
- 58% of all units are using morphine routinely to sedate preterm ventilated babies.

[57] *Arnon S, Dolfin T, Reichman B, et al. (2017) Delivery room resuscitation and adverse outcomes among very low birth weight preterm infants. J Perinatol.*

NICE quality standard QS193[58] states that preterm babies needing respiratory support soon after birth and before admission to the neonatal unit should be given continuous positive airway pressure (CPAP), if clinically appropriate, rather than invasive ventilation. This is also a longstanding recommendation in the European consensus guideline for management of respiratory distress syndrome as it is associated with a reduction in mortality as well as rates of BPD, also known as infant chronic lung disease (CLD).[59]

Based on BadgerNet data for 2016-19, the proportion of babies who were intubated and ventilated during initial management across ODNs ranged from 53-96% for babies <27 weeks gestation, 19-56% at 27-30 weeks (**Figure 26**) and 4-14% at 31-32 weeks. It was evident from network and trust visits that units and networks were at different stages of adopting a less invasive approach to early respiratory management and there is a need for network-wide guidance for preterm infant respiratory support in delivery suite to minimise use of mechanical ventilation.

Figure 26: Proportion of babies born 27-30 weeks, intubated, and ventilated during initial management at birth (MY2016/19)



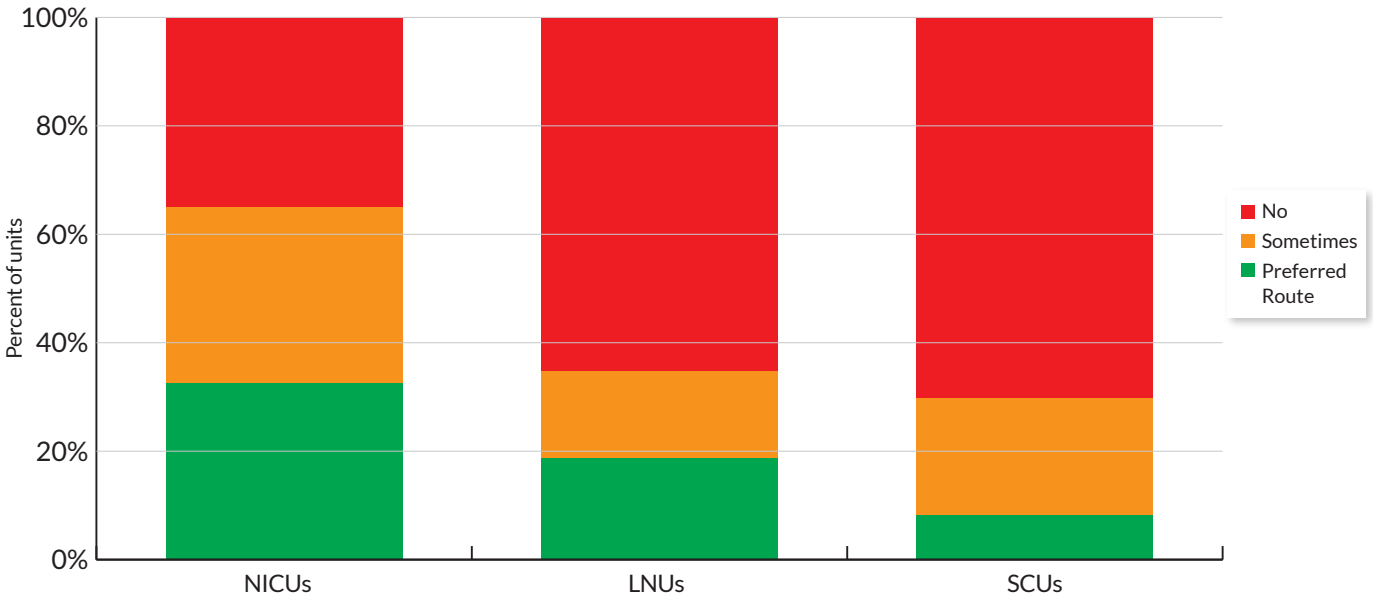
Source: BadgerNet

The second NICE quality standard is that preterm babies who need surfactant therapy (the administration of a liquid produced in the lungs to keep airways open) are given it using a minimally invasive technique (usually termed less invasive surfactant administration (LISA)) if they do not need invasive ventilation, as this reduces risk of BPD and pneumothorax. This is only occurring routinely in one third of NICUs and much less often LNUs and SCUs (**Figure 27**). On deep-dive visits it was evident that there are more units starting to use this technique. All networks and trusts should provide guidance and training in use of minimally invasive techniques for administering surfactant.

[58] *NICE (2020) QS193 Specialist neonatal respiratory care for babies born preterm*

[59] *Sweet DG, Carnielli V, Greisen G, et al. (2019) European Consensus Guidelines on the Management of Respiratory Distress Syndrome – 2019 Update, Neonatology www.karger.com/Article/Fulltext/499361*

Figure 27: Percentage of neonatal units using minimally invasive techniques to administer surfactant

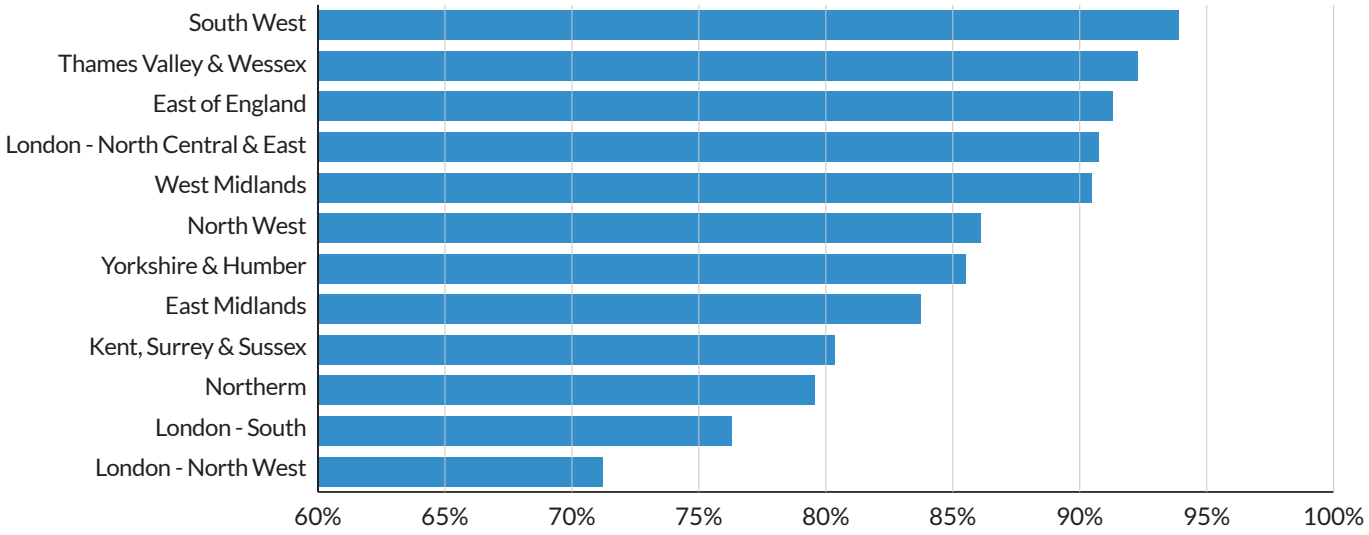


Source: GIRFT Clinical Services Questionnaire, November 2019

The third NICE quality standard is that preterm babies needing invasive ventilation receive synchronised volume-targeted ventilation as this again reduces the risk of death, BPD and pneumothorax. GIRFT data showed that 63% of units (86% of NICUs, 67% of LNUs and 32% of SCUs) were using this form of ventilation as their primary ventilation mode (GIRFT Clinical Services Questionnaire November 2019). Networks should provide guidance and training on use of synchronised volume-targeted ventilation and support units to develop business cases for purchasing ventilators able to deliver synchronised volume-targeted ventilation where these are not available. Consideration should be given to purchasing the same ventilator across LNUs and SCUs within a network to simplify training and potentially reduce costs.

NICE specialist neonatal care respiratory guidance recommends the use of caffeine citrate routinely in preterm babies born at or before 30 weeks, starting it as early as possible and ideally before three days of age. Results across ODNs (**Figure 28**) suggest this was achieved in 71-94% of cases (2018/19) although data entry for this item may not be fully completed across all units.

Figure 28: Percentage of babies < 30 weeks receiving caffeine within three days of life



Source: BadgerNet MY 2018-19

NICE also recommends that morphine should not be routinely used for preterm babies on respiratory support due to an increased risk of severe IVH and longer time to full feeds.[60] GIRFT clinical services questionnaire reveals that this is common practice in neonatal units with 58% of all units using morphine routinely to sedate a preterm ventilated baby.

Breast milk and feeding

GIRFT key findings:

- There is wide variation across networks and trusts in the percentage of infants who receive early mothers' milk (29-58% across ODNs on day 1).
- 60% of preterm babies are breastfed at discharge with no change in this figure since 2013 (NNAP).
- Access to donor milk for preterm babies is not routinely available to all units.
- 99% of neonatal units have standardised feeding guidelines for preterm infants at trust level but only 7 of 12 clinical networks have guidelines across part of or the whole network.

Maternal breastmilk is protective against necrotising enterocolitis (NEC), as well as having other health benefits including reducing rates of sepsis, improved neurodevelopmental outcomes and reduced rates of BPD.[61, 62, 63, 64] It is also an important part of developing a close relationship between mother and baby, supporting maternal mental health and wellbeing. The effects on baby last beyond the neonatal period, with reduced readmission to hospital, and reduced risks of long-term health issues such as obesity and type 2 diabetes.[65]

[60] *NICE (2019) NG124 Specialist neonatal respiratory care for babies born preterm https://www.nice.org.uk/guidance/ng124*

[61] *Patel AL, Johnson TJ, Engstrom JL, et al. (2013) Impact of early human milk on sepsis and health-care costs in very low birth weight infants. J Perinatol.*

[62] *Corpeleijn WE, de Waard M, Christmann V, et al. (2016) Effect of Donor Milk on Severe Infections and Mortality in Very Low-Birth-Weight Infants: The Early Nutrition Study Randomized Clinical Trial. JAMA Pediatr.*

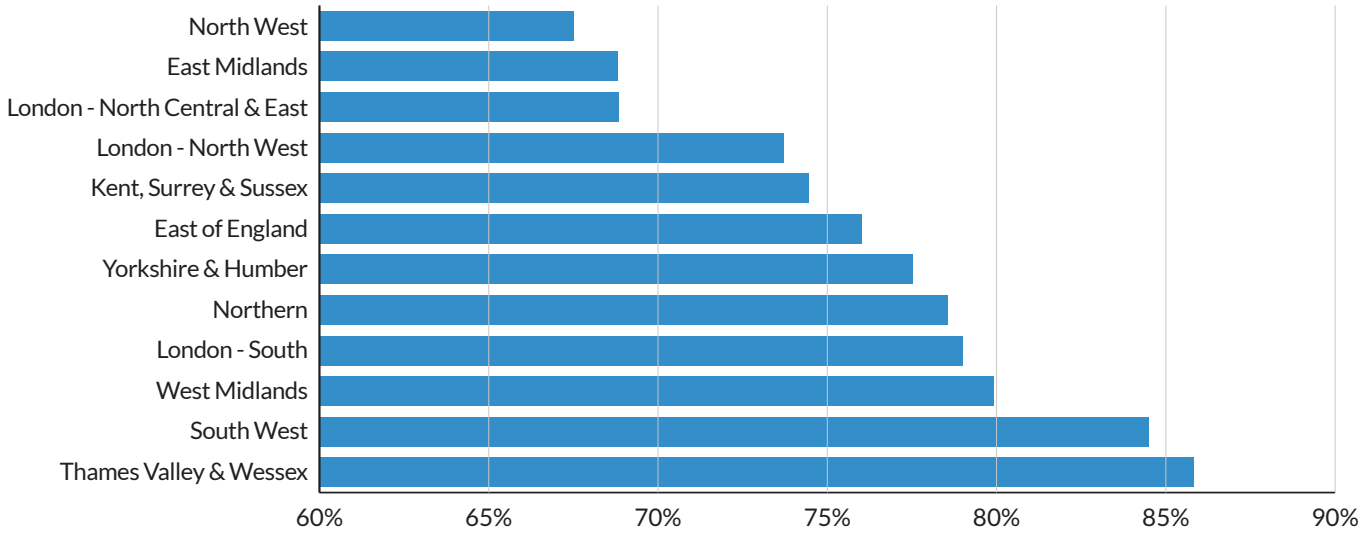
[63] *Belfort MB, Anderson PJ, Nowak VA, et al. (2016) Breast Milk Feeding, Brain Development, and Neurocognitive Outcomes: A 7-Year Longitudinal Study in Infants Born at Less Than 30 Weeks' Gestation. J Pediatr.*

[64] *Kim LY, McGrath-Morrow SA, Collaco JM. (2019) Impact of breast milk on respiratory outcomes in infants with Bronchopulmonary dysplasia. Pediatr Pulmonol*

[65] *Lewandowski AJ, Lamata P, Francis JM, Piechnik SK, et al. Breast Milk Consumption in Preterm Neonates and Cardiac Shape in Adulthood. Pediatrics. 2016 Jul;138(1):e20160050. doi: 10.1542/peds.2016-0050. Epub 2016 Jun 14. PMID: 27302980; PMCID: PMC6198929.*

Colostrum (first milk) should ideally be given within six hours to provide maximum benefit for the baby, and early and frequent milk expression is important for mothers to establish a good milk supply. We reviewed breast milk administration to preterm babies by day one and day three, which shows marked variation across different networks, breastmilk by day one ranged from 29-58%, increasing to 68-86% by day three (**Figure 29**).

Figure 29: Proportion of babies < 32 weeks receiving mother's milk/colostrum enterally or for mouth care within three days (MY2016/19)



Source: BadgerNet MY2016-19

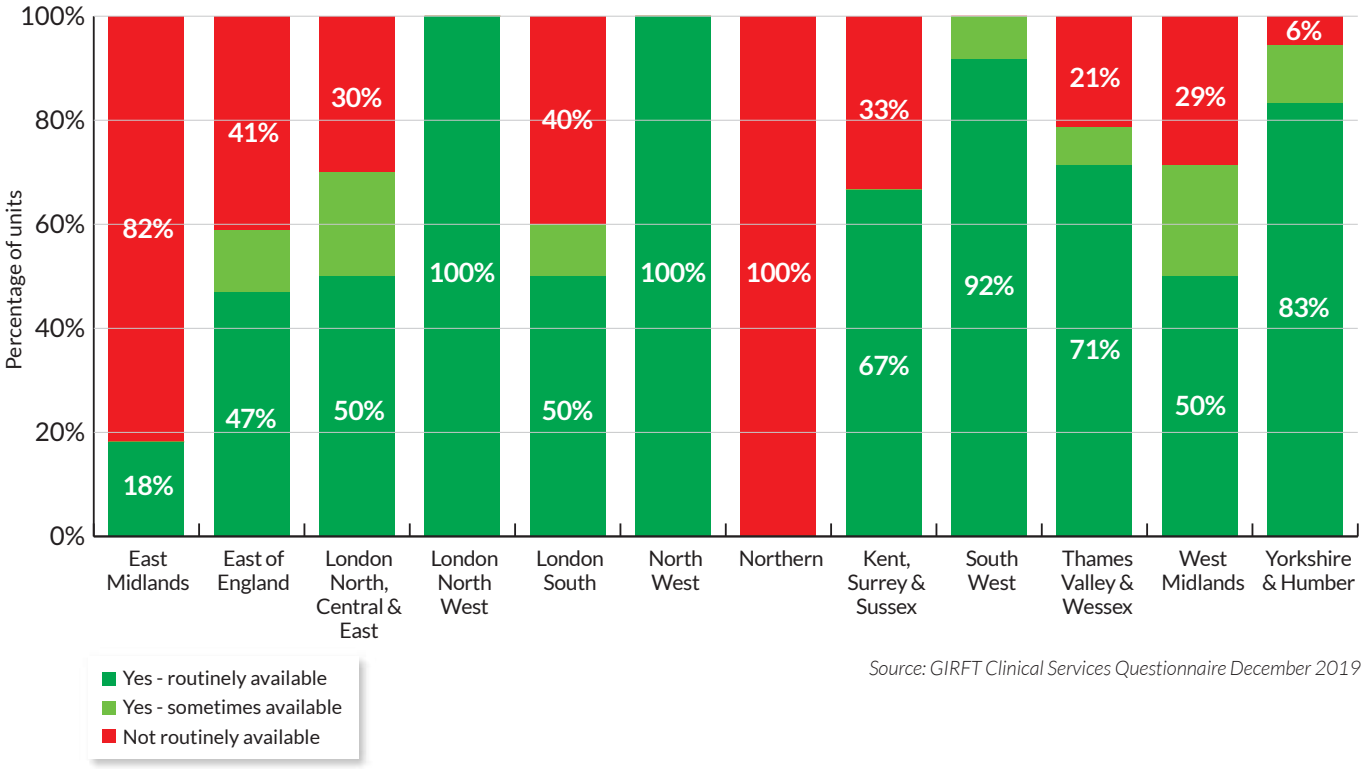
NNAP demonstrates wide variation in the proportion of preterm babies receiving some of their own mothers' milk at 14 days of age by neonatal network (76-88%), which is consistent with known geographical variation in breastmilk feeding of term babies in the UK. In addition, NNAP demonstrates approximately 60% of preterm infants are discharged home on some maternal breast milk, with no change in this figure since this was first measured in 2013.[66]

When maternal breast milk is not available, donor breast milk is associated with reduced NEC and is better tolerated than formula milk. This resource should be available in an equitable fashion for high-risk infants across a network.[67] Our data shows this is available for all units in some ODNs, but in many units, it is not routinely available (**Figure 30**).

[66] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data*

[67] *Arslanoglu S, Corpeleijn W, Moro G, et al. (2013) Donor human milk for preterm infants: current evidence and research directions. J Pediatr Gastroenterol Nutr*

Figure 30: Access to donor breast milk for pre-term infants (2019)



Source: GIRFT Clinical Services Questionnaire December 2019

Our data suggests that standardised feeding guidelines, another factor known to reduce NEC rates, are present in 99% neonatal units, and some networks have chosen to develop feeding guidelines across a clinical network or across the entire network. Where NEC rates are high, consideration should be given to whether a network guideline may be helpful.

Preterm infants: conclusions

There is much scope for improving neonatal mortality and a range of key long-term health outcomes in preterm infants by focussing on perinatal and early postnatal management in the first few days of life. These include:

- **Coordinated preparation:** good practice includes joined-up fetal and neonatal decision-making, and joint counselling for women who are expected to deliver at the limits of viability.
- **Antenatal management:** good practice includes being born in a NICU, timely administration of antenatal steroids, MgSO4 and antibiotics.
- **Delivery room management:** good practice includes optimal cord management, maintaining normothermia and minimising the use of invasive ventilation.
- **Early neonatal management:** good practice includes early caffeine administration, use of synchronised volume-targeted ventilation, LISA for surfactant administration, avoidance of routine use of morphine during ventilatory management and early maternal breast milk administration.

Review of care for preterm infants requiring higher levels of resuscitation: joint LMS/LMNS and neonatal ODN review of care for babies <27 weeks who receive cardiac compressions and/or adrenaline should be undertaken, to determine any common themes or actions to improve perinatal care. Once processes are established, units may wish to extend these reviews to cover infants up to 32 weeks.

There is also scope for improving the numbers of babies receiving breast milk during their entire stay in the neonatal unit. Where maternal breast milk is not available, there should be network guidance to support equal access to donated breast milk across the region for the most high-risk infants.

Improving these measures requires engagement and cooperation from maternity and neonatal services across the whole network. Fortunately, there is a wealth of excellent resources developed to support QI initiatives around start of life, including:

- The NNAP report, which includes excellent UK-wide benchmarking data with recommendations and signposting to resources for improving aspects of care.[68]
- Maternity Neonatal Safety Improvement Programme, which includes optimisation and stabilisation of the preterm infant as one of the focus areas for quality improvement.[69]
- BAPM QI toolkits, which give a comprehensive summary of the evidence for the measures included, along with tools and signposting to support quality improvement for local and/or network level implementation.[70] These cover antenatal optimisation, normothermia, optimal cord management and maternal breast milk.
- PERIPrem project, an ambitious and multifaceted perinatal improvement project with open access resources.[71]

IN PRACTICE

The PERIPrem project

West of England and South West Academic Health Science Networks

The PERIPrem project started in January 2020. The high-level aim is to improve survival free of brain injury in preterm infants. The project was funded and supported by the West of England and South West Academic Health Science Networks.

PERIPrem is a collaboration of all the 12 perinatal units in the South West with a high level of engagement of obstetricians, midwives, neonatologists/paediatricians, and neonatal nurses. The PERIPrem care bundle and tools were co-produced by the 12 perinatal teams and parent partners, supported by QI coaches and clinical leads. Parents with lived experience of preterm birth and neonatal intensive care are partners on the PERIPrem project team. They innovated by producing the PERIPrem baby passport and have been passionate advocates and advisors. Families helped to engage and encourage perinatal teams throughout the pandemic by telling their stories about their experiences of PERIPrem.

All QI/implementation tools, learning materials, coaching tools, run chart templates and PERIPrem baby passports are available for free download from the PERIPrem website, available at:
https://www.weahsn.net/our-work/transforming-services-and-systems/periprem/

PERIPrem uses the same clinical leadership model developed in PReCePT, with a dedicated nurse and midwife champion in each unit, supported by a unit obstetric and neonatal consultant and regional clinical leads with overall oversight. The teams are supported by AHSN QI coaches, to help focus development and refining of the elements in the care bundle.

Each of the ten elements of the care bundle is evidence-based, and the combined benefit to preterm infants is an estimated 50% reduction in mortality and severe brain injury (11th element added in 2021). A comprehensive set of measurement tools were developed, enabling each unit and the entire region to measure improvement in uptake of each of the elements/interventions at patient level at monthly intervals. From September 2020, complete data have been submitted by all units. In February 2020 the optimisation score for the region was 70%, meaning that 70% of all indicated interventions (by gestation) were received.

In addition, UNICEF Neonatal Baby Friendly Initiative (BFI)[72] provides an evidence-based programme to improve support for breast milk production and breastfeeding in neonatal units, and implementation of this programme is strongly recommended (also see *Supporting Families*). Funding sources should be sought at local and national level. Funding is on offer for maternity services to support UNICEF maternity BFI accreditation through the NHS Long Term Plan and there is a strong case for central funding for the separate UNICEF Neonatal BFI accreditation.[73]

[68] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data www.rcpch.ac.uk/sites/default/files/2020-11/nnap_report_2020_final_pdf2.pdf*
[69] *https://www.england.nhs.uk/wp-content/uploads/2020/08/20190308_Optimisation_v2.1.pdf.*
[70] *www.bapm.org/pages/104-qi-toolkits)*
[71] *www.weahsn.net/our-work/transforming-services-and-systems/periprem/*
[72] *https://www.unicef.org.uk/babyfriendly/accreditation/*
[73] *https://www.UNICEF.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/neonatal-guide-to-the-standards/*

Deep-dive visits suggested a high level of interest in these improvement projects, but some concerns were expressed regarding the time available to undertake multiple projects. All trusts and networks should review available benchmarking data to develop formal annualised QI plans to support improvements in optimal start interventions (and other interventions where planned). Trust level plans should be submitted to the network.

Networks and trusts should utilise the national QI tools to improve optimal start metrics. Sharing of resources, data analyst support and shared practice will reduce the burden on individual units and provide a supportive structure for improvement with a focus on items most likely to impact outcomes both at network and unit level. Perinatal working, with close maternity and neonatal collaboration at network and unit level is essential to the success of these QI projects.

Although every effort should be made to ensure high-risk babies are born in NICUs, a number of babies who require significant intensive care support will continue to be born in LNUs and SCUs. Supporting education and training in early preterm stabilisation and other emergency scenarios through simulation sessions and practical skills refresher courses (at least annually, ideally bi-annually) and supernumerary time for LNU/SCU staff to spend in the NICUs is extremely important to maintain skills and confidence in situations which occur infrequently outside the NICU setting. Time both for teaching and attending such events must be prioritised by networks and trusts.

In addition, rapid access to expert clinical advice during stabilisation and intensive care support should always be available and networks and transport services should look at ways to improve this through use of new technologies including telemedicine.

IN PRACTICE

A neonatal telemedicine service

Liverpool Neonatal Partnership

During the pandemic, a telemedicine service was introduced into Liverpool Neonatal Partnership (LNP), consisting of the NICU at Liverpool Women's Hospital (LWH) and Alder Hey Children's Hospital (AHCH). The system is currently used by the Mayo Clinic to improve quality of neonatal care across its networked hospitals.

The service was introduced early in the pandemic as the LNP was unable to staff both sites due to the loss of 50% of the consultant workforce from sickness, self-isolation and shielding. Telemedicine 'robots' were implemented on both sites. The shielding and isolating consultant workforce who were at home were trained remotely on how to access the telemedicine system which took 15 minutes per consultant. A rota for the new 'virtual consultant' was formed, which included full ward round cover for the neonatal surgical unit on the AHCH site and the low dependency unit on the LWH site.

Families accepted this new way of working and one consultant commented on how even having never met families in person, he was able to develop a relationship with them. This allowed the consultants at home to continue to provide a full clinical service and the clinicians who were able to provide face to face consultations provided the care on the high-dependency and intensive care units. **One virtual consultant replaced 66 hours per week of consultant time.**

The surgeons, to reduce footfall and allow them to remain on site at AHCH, used the robot at the LWH site to be able to review babies remotely within a few minutes of being contacted. The resolution on the cameras on the robots was such that close review of babies' abdomen's, wounds and stomas was easily possible. The system was also used to connect the echocardiography machine to the device allowing remote specialist review of images.

The use of the telemedicine system has expanded to cardiology, plastic surgery and other specialities.

The service is undertaking a survey on parent experience of the telemedicine system and is working with the Mayo Clinic to carry out an accompanying research programme comparing telemedicine as an outcome compared to traditional care. In conjunction with North West ODN, the service is seeking to implement tele-neonatology across the network, supporting local neonatal units in the provision of neonatal care.

[74] *Ockenden D (2020) Emerging Findings and Recommendations from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust https://www.donnaockenden.com/downloads/news/2020/12/ockenden-report.pdf*

Neonatal haematology and transfusion practices

GIRFT key findings:

- 53% of units would never or rarely perform a coagulation screen routinely during first 24 hours for a well preterm infant at 28 weeks.
- 36% of units use platelet transfusion threshold 25 x109/L for well preterm neonates (evidence-based guidance).
- NICUs were more likely than LNUs and SCUs to follow BSH guidelines regarding routine coagulation screens and platelet transfusion thresholds in well preterm neonates.

Transfusion of blood components in the neonatal period is not an infrequent occurrence, with most transfusions given to preterm infants <32 weeks due to low circulating blood volume, frequent blood sampling, anaemia related to inflammation and anaemia of prematurity. Neonates and children are considered to be at higher risk of adverse events compared with adults (Serious Hazards of Transfusion (SHOT))[75] and unnecessary transfusion should be avoided. Best practice guidelines for neonatal transfusion are produced by the British Society for Haematology (BSH) and recommendations are helpfully summarised in a neonatal transfusion summary bookmark.[76, 77, 78] This guidance recommends that routine coagulation screening is considered inappropriate as results are difficult to interpret in neonates and routine testing may lead to increased unnecessary fresh frozen plasma (FFP) transfusion, but our data suggests this guidance is not being followed in many units (see **Figure 31**).

The BSH also recommended a threshold for platelet transfusion in non-bleeding preterm neonates of <25 x10^9/L. This was recently strengthened to state that platelets should not be routinely transfused to non-bleeding preterm neonates with platelets ≥ 25 x10^9/L, following a randomised control trial (RCT) comparing transfusion thresholds at 25 x10^9/L and 50 x10^9/L which demonstrated higher rate of mortality or major bleeding in the higher threshold arm. Only one third of all units use the transfusion threshold of 25 x10^9/L for a well preterm infant, with this being more likely in NICUs than LNUs and SCUs (**Figure 32**).

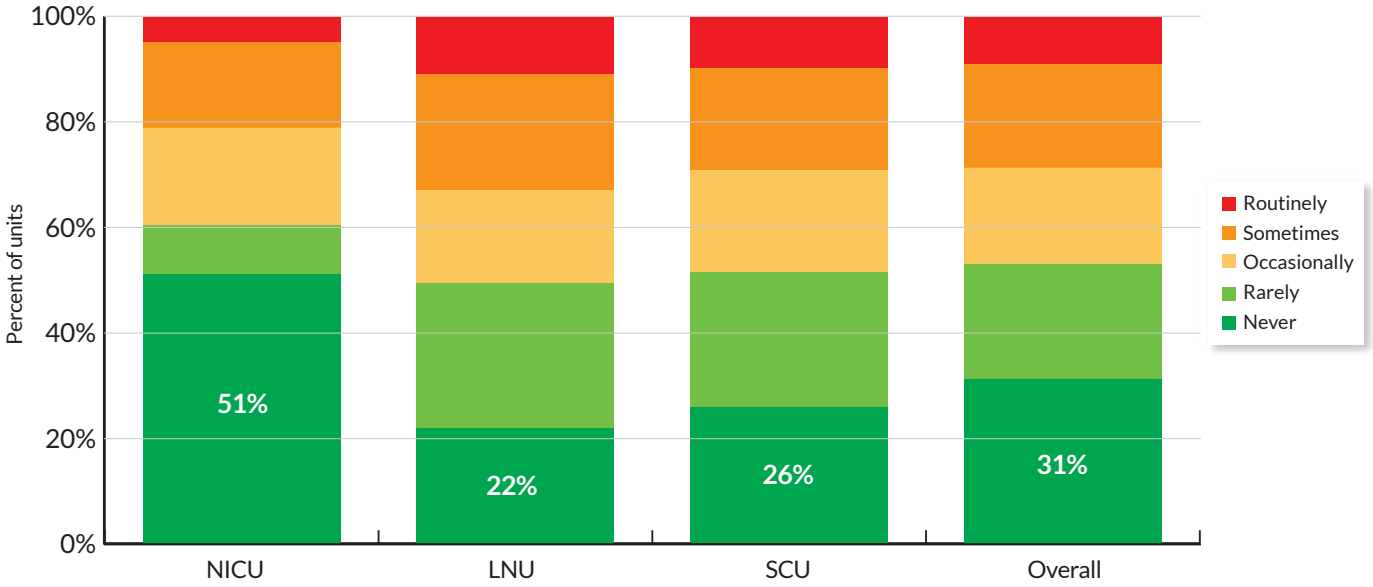
[75] *www.shotuk.org/wp-content/uploads/myimages/SHOT-Bite-No-4-Lessons-in-Paediatrics-July-2018.pdf*

[76] *https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/21548/blc7371p-nov-2020-neonates-bookmark.pdf*

[77] *British Society for Haematology (2016) Transfusion for Fetuses, Neonates and Older Children https://b-s-h.org.uk/guidelines/guidelines/transfusion-for-fetuses-neonates-and-older-children/*

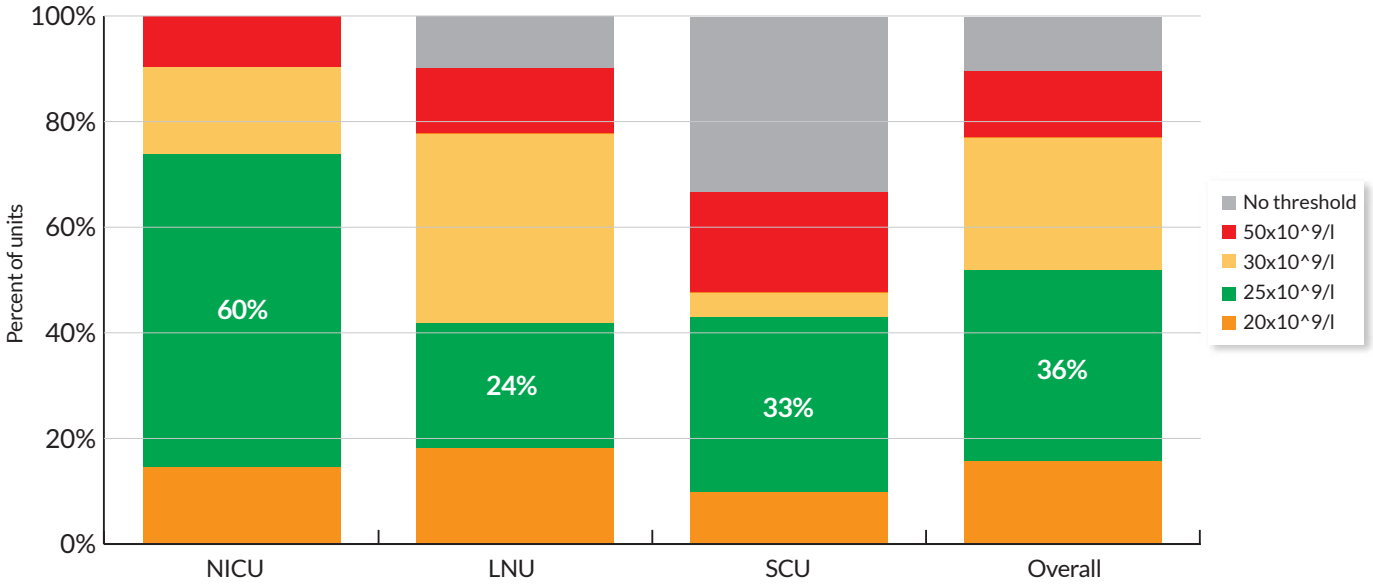
[78] *https://www.shotuk.org/wp-content/uploads/myimages/Neonatal-Transfusion-Bookmark-2017.pdf*

Figure 31: Routine coagulation screens in well preterm infants at 28 weeks (% of units)



Source: GIRFT Clinical Services Questionnaire December 2019

Figure 32: Thresholds for platelet transfusion well preterm infant (1 week old, 28 weeks' gestation baby)



Source: GIRFT Clinical Services Questionnaire December 2019

There was variation in volumes of blood or platelets that would be given ranging from 5 to 20ml/kg with the majority giving 10 or 15 mL/kg. It is unclear what the optimal transfusion volume should be, but it is recognised that these volumes are proportionately larger than those used in adult practice.

It is clear from these results that best practice information regarding transfusion does not universally reach clinicians working on the ground. For this reason, network-wide guidance on transfusion practice for neonates based on national guidelines should be developed by haematologists and neonatologists with an interest in neonatal haematology to provide consistency of practice across all units and to reduce unnecessary transfusion, donor exposure and adverse outcomes of transfusion. In addition, staff prescribing blood components for neonates should have appropriate transfusion training and this should include reviewing key educational messages from annual paediatric SHOT reports.[79, 80]

Prevention of transfusion is also important and increasing the number of preterm babies receiving optimal cord management will reduce mortality and the need for transfusion of fresh frozen plasma, platelets and blood. In addition, neonatal units should audit blood testing practices aiming to eliminate unnecessary tests and minimise blood volumes taken, to reduce the need for transfusion and minimise painful procedures. Further research trials are needed to improve safe and effective transfusion practice in neonates and neonatal units should be encouraged to participate in new studies.

Bilious vomiting and neonatal radiology services

GIRFT key findings:

- 974 upper GI contrast studies were performed on term neonates <7 days old in the first two weeks of life.
- Contrast studies occurred in only 42 trusts with >50% studies undertaken by six hospitals.
- Only 1/3 of NICUs have 24/7 access to upper GI contrast studies.
- Not all neonatal transport services can accommodate transferring babies with bilious vomiting.
- Some networks have developed drive-through services for well babies requiring upper GI contrast studies to reduce mother-baby separation and unnecessary admission to the surgical neonatal unit.

Babies who vomit bile require urgent review and upper gastro-intestinal (GI) contrast study to exclude malrotation which may obstruct the flow of blood to the gut with potential catastrophic loss of bowel. The proportion of neonates with bilious vomiting that are subsequently diagnosed with surgical pathology varies between 11-50% in published literature.[81, 82, 83]

In 2018/19, 721 term infants (37+ weeks gestation) admitted to neonatal units in the first week of life had 974 upper GI contrast studies within the first 14 days. Almost all these babies will have received the contrast study to rule out malrotation or major obstruction because of bile-stained vomiting. It is possible that this data may underrepresent the full picture due to combining of data sets and the possibility that some babies may not have been admitted to the neonatal unit. Only a quarter of neonatal units (56% of NICUs, 20% of LNUs and 5% of SCUs) did at least one GI contrast study in the FY2018/19. Two hospitals undertook a quarter of all studies nationally, with more than 50% of all studies undertaken by just six hospitals (**Figure 33**).

[79] *https://www.shotuk.org/shot-reports/*

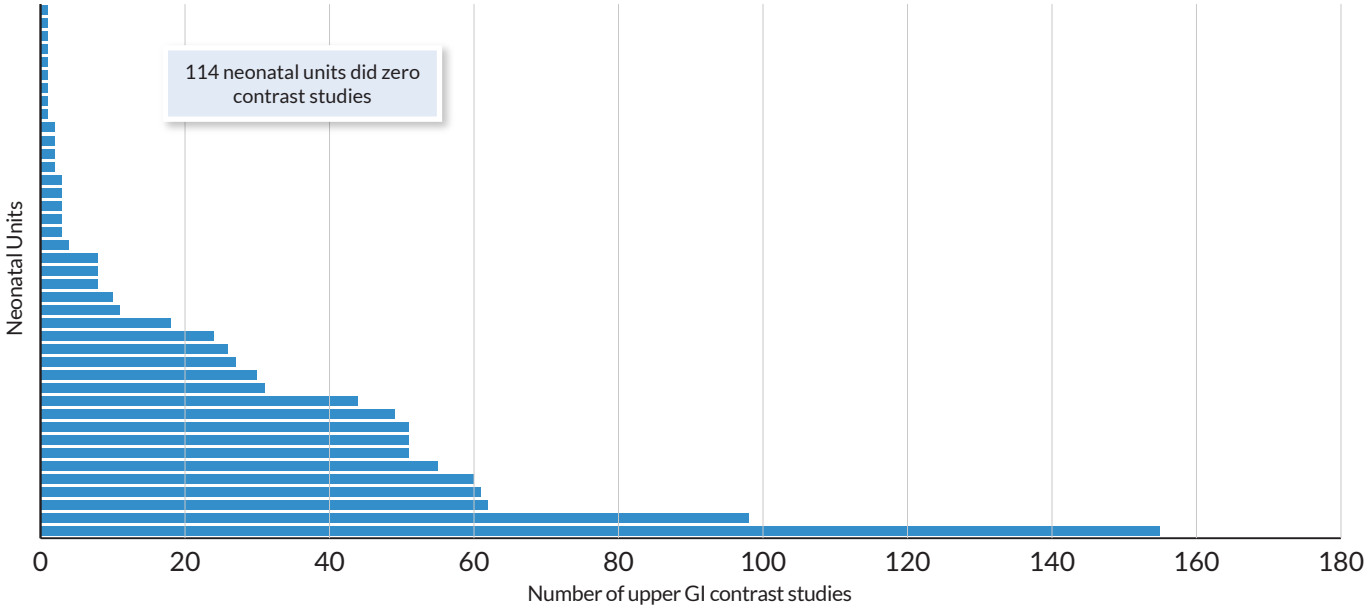
[80] *https://www.shotuk.org/resources/current-resources/videos/*

[81] *Borooah M, Narang G, Mishra A, et al. (2010) Bilious vomiting in the newborn period: surgical incidence and diagnostic challenges. Arch Dis Child*

[82] *Mohinuddin S, Sakhuja P, Bermundo B, et al. (2014) Outcomes of full-term infants with bilious vomiting: observational study of a retrieved cohort. Arch Dis Child*

[83] *Cullis PS, Mullan E, Jackson A, Walker G. (2018) An audit of bilious vomiting in term neonates referred for pediatric surgical*

Figure 33: Number of upper GI contrast studies in FY2018/19

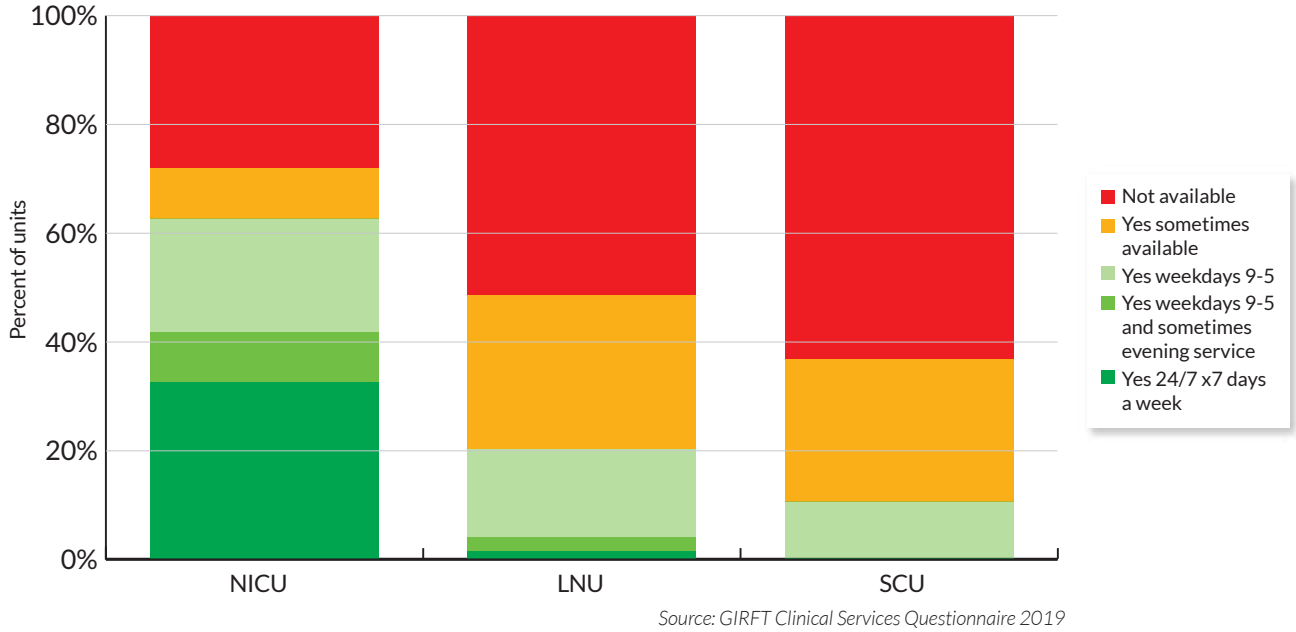


Note: The chart combines data from two sources and there may be some double counting of upper GI contrast studies. However, this overlap is likely to be minor and does not alter the overall finding.

Source: HES FY2018/19 / DIDS FY2018/19

Access to upper GI contrast studies is very patchy with only a third of NICUs having 24/7 access (**Figure 34**). Surprisingly, even some surgical NICUs did not have a 24-hour service. There was a mix of provision, with some services wholly provided by paediatric radiology and others where the service was shared with adult radiology colleagues. Deep-dive visits revealed that problems with access to radiology and radiography services are not confined to upper GI contrast studies and include problems accessing portable plain X-rays in some units out of hours, with standalone maternity hospitals particularly vulnerable to gaps in service or no on-site services after hours. There was also variable provision for neonatal ultrasound.

Figure 34: Availability of upper GI contrast studies in neonatal units



Source: GIRFT Clinical Services Questionnaire 2019

This data, together with information from deep-dive visits, suggests that a large number of babies are requiring urgent transfer to another hospital, often out of hours, for an upper GI contrast study and surgical review, followed by a subsequent journey back to their local hospital in most cases. In FY 2020-21 there were 779 transfers for bilious vomiting done by UK neonatal transport services which is an underrepresentation of the total transfers undertaken.[84] This puts a significant burden on neonatal transport services, reducing availability of the service for other sick neonates, and often results in unnecessary mother-baby separation. In some regions transport services do not have the capacity to support transfer of these babies and local hospitals are required to undertake the transfer themselves. GIRFT has learnt from deep-dive visits that this results in variable quality of transport service provision due to infrequent transfer experience, significant delays for some services in time taken to perform contrast study due to delays in accessing the regional ambulance service and pressure on both the local ambulance service and local hospital teams. This may also result in an unnecessary admission to surgical NICUs.

The service is currently inequitable, with some neonatal units of all designations being unable to access contrast studies at least some of the time. Paediatric radiology is a shortage area and maintaining fluoroscopy skills after completion of training CCT is difficult outside children's hospitals and acute hospital departments with a large throughput. For this reason, networked provision is likely to be required, particularly out of hours. Some transport services have a pathway to provide 'drive-through' service, whereby the baby is transported direct to the radiology department in the receiving hospital for a contrast study. They are seen and reviewed by the surgical team and, if there is no pathology, the transport team repatriate the baby straight back to the referring unit without admission to the surgical NICU.

It is recommended that consideration be given to development of a national framework for practice for babies presenting with bilious vomiting. This should be developed by a multidisciplinary working group including neonatologists, paediatric surgeons, neonatal transport services and paediatric and adult radiologists. There is also a need for the development of standards for provision of radiology/radiography services in NICUs (both medical and surgical centres), LNUs and SCUs. Networks should review their pathway for babies with bilious vomiting and work with all service providers to improve this pathway, including minimisation of mother-baby separation. Consideration should be given to developing drive-through pathways for well infants.

[84] *NTG National Transport Group (NTG) benchmark data, 2020/21*

Recommendations to improve clinical aspects of neonatal care

Recommendation	Actions	Owners	Timescale from date of publication
5. Improve attainment of key optimal start metrics for preterm infants. These include the following core items: • born in NICU; • antenatal steroids; • antenatal MgSO4; • antenatal antibiotics; • Optimal cord management; • normothermia on admission to NICU; and • colostrum within 24 hours.	**a** Review available benchmarking data to develop formal annualised QI plans at trust and neonatal ODN level to support improvements in optimal start interventions (and other interventions where planned). Trust-level plans should be submitted to their network.	Neonatal ODNs and trusts	12 months
	b Utilise national QI resources e.g. BAPM/ MatNeoSIP to improve optimal start metrics. Sharing of resources, data analyst support and shared practice will reduce the burden on individual units and provide a supportive structure for improvement.	Neonatal ODNs, trusts, AHSNs and MatNeoSIP	Immediate and ongoing
	c Increase perinatal working, with close maternity and neonatal collaboration at network, transport and unit level to improve optimal start metrics.	Neonatal ODNs, trusts and LMSs/LMNSs	Immediate and ongoing
	d Establish a joint review by LMSs/LMNSs and neonatal ODNs of preterm babies <27 weeks who received higher levels of resuscitation (cardiac compressions and/or adrenaline) to review outcomes and determine any common themes or actions to improve perinatal care.	Neonatal ODNs and LMSs/LMNSs	1 – 2 years
6. Maintain skills and confidence for all neonatal clinical staff, particularly those working in LNUs and SCUs, managing emergency situations which occur infrequently outside the NICU setting.	**a** Provide education and simulation training, at least annually but ideally bi-annually, for the entire workforce to ensure confidence and skills are maintained in early preterm stabilisation and other emergency scenarios requiring neonatal emergency procedures, such as exchange transfusion and chest drain placement.	Neonatal ODNs, trusts and LMSs/LMNSs	12 months
	b Offer supernumerary time for LNU/SCU staff to spend in NICUs to increase exposure to intensive care.	Trusts	1 – 2 years
	c Look at ways to improve rapid access to expert clinical advice during stabilisation and intensive care support, including use of new technologies such as telemedicine.	Neonatal ODNs, trusts, neonatal transport services	2 – 5 years
7. Implement NICE guideline NG124 specialist neonatal respiratory care for babies born preterm.	**a** Develop local guidance for preterm infant respiratory support in delivery suites to minimise use of mechanical ventilation.	Neonatal ODNs and trusts	6 – 12 months
	b Provide guidance and training in use of minimally invasive techniques for administering surfactant.	Neonatal ODNs and trusts	12 months
	c Provide guidance and training on use of synchronised volume-targeted ventilation.	Neonatal ODNs and trusts	24 months
	d Support units to develop business cases for purchasing ventilators that are able to deliver synchronised volume-targeted ventilation. Consideration should be given to purchasing the same ventilator across LNUs and SCUs within a network to simplify training and potentially reduce cost (see also recommendation 21).	Neonatal ODNs and trusts	1 – 2 years

Recommendation	Actions	Owners	Timescale from date of publication
8. Improve early access to breast milk and sustaining numbers of preterm babies receiving breastmilk during their entire stay in the neonatal unit.	**a** Use the BAPM Breastmilk Toolkit to improve the numbers of preterm babies receiving breastmilk during their entire stay in the neonatal unit.	Neonatal ODNs, trusts	6 – 12 months
	b UNICEF Neonatal BFI accreditation is strongly recommended, and funding sources should be sought at local and national level. Funding is on offer for maternity services to support UNICEF Maternity BFI through the NHS Long Term Plan and there is a strong case for central funding for UNICEF Neonatal BFI accreditation.	NHSE National specialised commissioning team, Maternity Transformation Programme, LMSs/LMNSs, neonatal ODNs and trusts	1 – 3 years
	c Improve network guidance to support equal access to donor breastmilk across the region for the most high-risk infants.	Neonatal ODNs	6 – 12 months
9. Reduce unnecessary transfusion of blood components, donor exposure and adverse outcomes of transfusion in neonates.	**a** Locally adapt and implement network-wide guidance on transfusion for neonates based on national best-practice guidelines.	Neonatal ODNs	12 months
	b Provide appropriate transfusion training to all staff prescribing and administering blood components for neonates, including reviewing key educational messages from paediatric reports in the national haemovigilance system (SHOT).	Trusts	12 months
	c Audit blood testing practices with the aim to eliminate unnecessary tests and minimise blood volumes taken.	Trusts	1 – 2 years
	d Conduct further research trials to improve safe and effective transfusion practise in neonates and neonatal units should be encouraged to participate in approved trials.	Clinical academic neonatal practitioners / haematologists/ Trusts	2 – 5 years
10. Improve the pathway for babies presenting with bilious vomiting to reduce unnecessary transfers and reduce delays in access to surgical review and upper GI contrast study.	**a** Develop a National Framework for Practice for babies presenting with bilious vomiting with involvement of a multidisciplinary working group.	BAPM, BAPS, NTG, BSPR, RCR	1 – 2 years
	b Form a cross-party working group, including service user representation, to develop standards for radiology / radiography services needed in NICUs, LNUs and SCUs.	BAPM, BSPR, RCR, SCoR	1 – 2 years
	c Review pathways for babies with bilious vomiting and work with surgical NICUs, transport services and all service providers to improve the pathway, including minimising mother-baby separation. Consideration should be given to developing "drive-through" pathways for well infants.	Neonatal ODNs, surgical NICUs, patient transport services, paediatric radiology and radiography	1 – 3 years

Clinical governance, safety and litigation

There have been a number of initiatives to improve governance, safety and reduce litigation risks in neonatal and maternity care over the last few years. In this section, we will review the progress made with governance arrangements in line with recommended national safety actions. In addition, we discuss drug safety, assessment and treatment of neonatal jaundice and current use of pulse oximetry screening in neonatal care, as well as reviewing the learning and safety actions arising from litigation cases in neonatology.

Governance structures and morbidity and mortality review

GIRFT key findings:

GIRFT data, December 2019 showed:

- 60% of neonatal operational delivery networks (ODNs) reviewed all deaths with variable maternity involvement.
- 20-30% of networks had oversight of trust Perinatal Mortality Review Tools (PMRT) and local mortality processes.
- 30% of ODNs were involved with Child Death Overview Panels (CDOP) process.
- 57% of trusts were reviewing all deaths, and a further 35% reviewed all on-site deaths.
- Half of units were using the PMRT for all deaths <28 weeks.

Governance arrangements and morbidity and mortality review at both network and trust level have undergone significant change and improvement in the last few years.

Action on Neonatal Mortality was issued by NHS England Specialised Commissioning to all Local Maternity Systems/Local Maternity and Neonatal Systems (LMSs/LMNSs) in August 2017. This recommended action to ensure that all neonatal deaths were investigated at a local level using a standardised framework; LMSs/LMNSs and ODNs should ensure that all deaths in the delivery room and neonatal unit from 23 weeks' gestation are investigated; and lessons learned from reviews should be implemented and shared through regional maternity boards.

In 2018, the new Child Death Review Process[85] was published and the Perinatal Mortality Review Tool (PMRT)[86] was launched. In addition, there has been significant focus on improving safety through the NHS Resolution Maternity Incentive Scheme for Trusts,[87] which commenced in FY2018/19 and has very focussed actions for trusts that will improve safety and reduce risks for both mothers and babies, including use of the PMRT (safety action 1). The Health Safety Investigation Branch (HSIB) maternity investigations commenced in 2018 and provide independent investigation of stillbirths, early neonatal deaths and potential severe brain injury, in babies born at term. The HSIB shares findings, recommendations and general themes with trusts, LMSs/LMNSs and nationally.

At a national level, *Each Baby Counts*, the Royal College of Obstetricians and Gynaecologists (RCOG) quality improvement programme, brings together the results of local investigations into stillbirths, neonatal deaths and brain injuries occurring during term labour to understand the bigger picture. It makes a range of recommendations to ensure each baby receives the safest possible care during labour.[89]

Network governance

All networks hold regular governance meetings and there has been significant improvement in co-ordinated working between LMSs/LMNSs and neonatal ODNs in most but not all networks over the last 18 months. The pandemic has created some useful structures for joint working at regional and national level, such as the creation of a specialised commissioning mat-neo cell in the Midlands, and regular national neonatal ODN–specialised commissioning meetings. These structures have been significantly aided by the more universal availability and adoption of online meeting facilities. All neonatal ODNs must have a clear governance and communications structure to specialised commissioning teams in place.

[85] *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf*

[86] *https://www.npeu.ox.ac.uk/pmrt*

[87] *https://resolution.nhs.uk/wp-content/uploads/2021/03/Maternity-Incentive-Scheme-year-3-March-2021-FINAL.pdf)*

[88] *https://www.hsib.org.uk/maternity/*

[89] *RCOG (2019) Each Baby Counts: 2019 progress report*
https://www.rcog.org.uk/globalassets/documents/guidelines/research--audit/each-baby-counts/each-baby-counts-2019-progress-report.pdf

Nearly all networks hold network-level risk registers but there is variability in how actively these were used and, in some networks, there is less clarity about how to escalate risk at a regional level. All networks should review the network risk register quarterly and have clearly outlined processes for escalation of risk from trusts to network and from network to region.

Network mortality review

There was significant variation in the level of network involvement in mortality review processes (**Table 3**). At the time of our survey in November 2019, only six networks reviewed all deaths, a further two reviewed selected cases, and two did not have any mortality review. By the time of our network deep-dive visits, a further network had established a review process and there were plans to establish this in the remaining network.

There is considerable progress required in most networks to ensure a standardised process for review of all neonatal deaths across the network which includes LMS/ LMNS and maternity representation. Allowing ODNs to access selected data from live PMRT reporting would strengthen network oversight and standardisation of reviews.

Only 30% of networks are involved in the Child Death Overview Panels (CDOP) with several networks expressing difficulty in obtaining access at deep-dive visits. Greater involvement of networks in the CDOP process is required to provide a more robust mortality review framework.

Table 3: Network processes for reviewing neonatal deaths

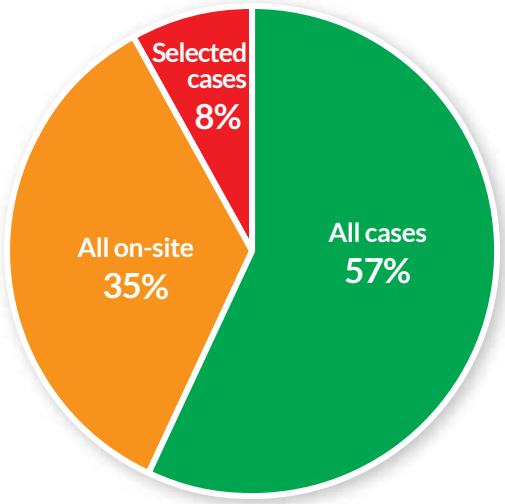
	% of networks
Trust confirmation of PMRT completion	30%
Trust confirmation of local morbidity and mortality meetings	20%
Network death review reporting tool	60%
Network management team review of deaths	50%
Network Clinical Mortality Review Group	70%
Network involvement in CDOP process	30%

Source: GIRFT Clinical Questionnaire December 2019

Trust mortality reviews

At trust level, 57% of neonatal units were reviewing all neonatal deaths at the time of our survey in 2019, with a further 35% reviewing deaths occurring on-site but excluding those moved to another location (**Figure 35**). 8% of trusts were reviewing selected cases. Increased use of online meeting technology has improved the ability for clinicians to be involved in local morbidity and mortality review outside their own trust (supporting discussion of the full care pathway for babies who have received care in multiple locations prior to death) as well as facilitating network morbidity and mortality review attendance.

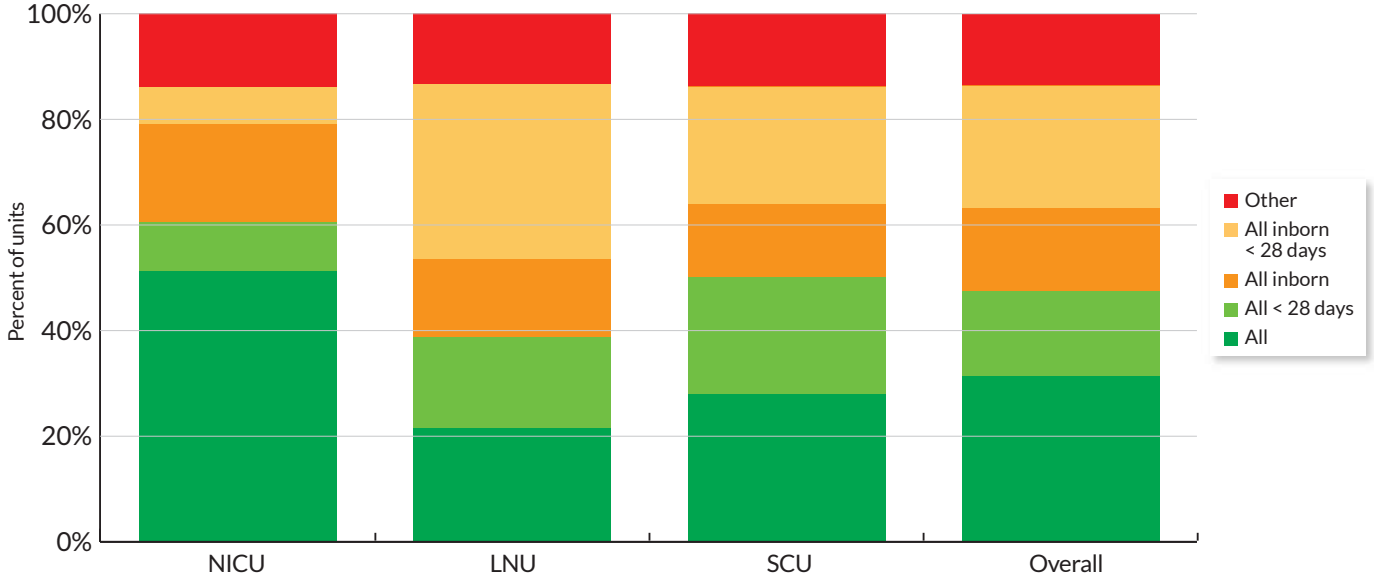
Figure 35: Percentage of neonatal units reviewing neonatal deaths at local morbidity and mortality meetings



Source: GIRFT Clinical Services Questionnaire, December 2019

The PMRT provides a standardised structure to approach perinatal mortality review. The NHS Resolution Maternity Incentive Scheme Safety Action 1 requires that neonatal deaths up to 28 days after birth are reviewed, but the tool can be used for deaths beyond 28 days. **Figure 36** shows the level of use of the PMRT tool at the time of the questionnaire in 2019 and shows that even at this time, half of NICUs were using this tool for all deaths. Due to the requirements of the maternity incentive scheme, use will now be much higher across all units for all infants <28 days.

Figure 36: Use of the Perinatal Mortality Review Tool by neonatal units



Source: GIRFT Clinical Services Questionnaire December 2019

There must be a coordinated approach to maternity and neonatal governance. Whilst recognising that particular issues may require more in-depth focus at specialty level, there must be appropriate overarching structures for both governance and mortality review. This is an important activity and time should be made available in job planning to ensure that teams can actively engage in review activities. All neonatal deaths should be reviewed with timely notification of deaths to MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries), completion of PMRT in line with Maternity Safety Incentive Scheme requirements and statutory notification requirements for the CDOP. Trusts should make use of videoconferencing to ensure external review.

Drug safety

The World Health Organisation has made reducing patient harm due to medication errors (ME) its current global patient safety challenge with the aim of reducing severe harm associated with MEs by 50% within 5 years.[90] Although drug errors are common across all specialties, there are specific issues raised in neonatology due to the size of the patients, the need for weight-based prescribing and rapidly changing weight, the need for dilution of medication and frequent off-label use.

Medication related events are one of the top three reasons for incident reporting in most neonatal units, particularly in LNUs (**Table 4**) and are also a cause of clinical negligence claims (discussed in more detail below). Shared learning from medication related incidents should be disseminated at local and network level and incorporated into education programmes.

Table 4: Incidents involving medication, drugs or prescribing issues in neonatal units

Designation	Top incident	Top three incidents
NICU	28.0%	62.7%
LNU	51.2%	81.4%
SCU	7.9%	39.5%
Overall	29.5%	62.2%

Source: GIRFT Clinical Services Questionnaire December 2019

Interventions to reduce medication errors in neonatal care include electronic prescribing, standardised prescribing, use of electronic clinical calculators, 'smart' pump technology, education and training, pharmacy-prepared ready to use drugs/infusions, as well as the presence of an experienced neonatal pharmacist in the neonatal unit (see our discussion about AHPs in the *Workforce report*).[91] Information gathered during deep-dive visits suggests there is scope for improving safety.

Electronic prescribing

GIRFT key findings:

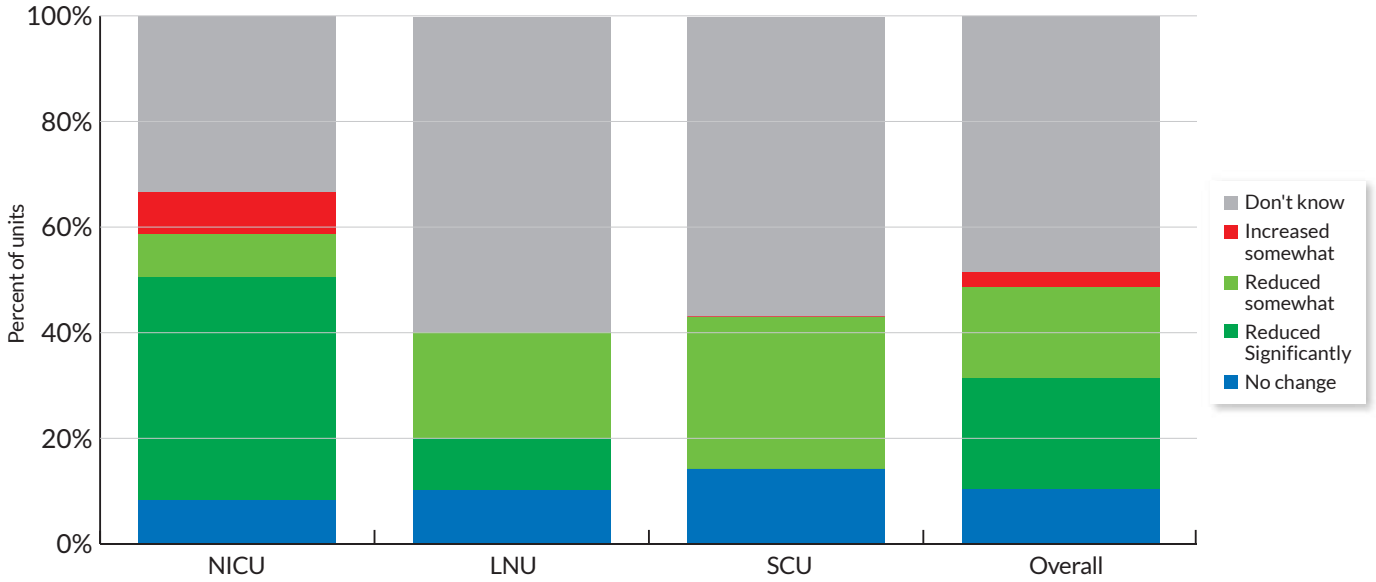
- 62% of units had medication issues in top three reasons for incident report.
- Only 19% of neonatal services were using electronic prescribing (EP), and this was highest in NICUs (28%).
- 38% of units who had EP felt this had improved drug errors.

[90] *World Health Organization (2017) WHO global patient safety challenge: medication without harm. In: Patient safety. https://www.who.int/patientsafety/medication-safety/en/*

[91] *Nguyen MR, Mosel C, Grzeskowiak LE. (2018) Interventions to reduce medication errors in neonatal care: a systematic review. Ther Adv Drug Saf.*

GIRFT asked trusts whether they were using electronic prescribing (EP) and found that only 19% were, with highest percentage in NICUs (28%). Of those that were using electronic prescribing 38% felt that changing to electronic prescribing had improved drug errors, with 42% of NICUs feeling this change had resulted in a significant improvement in drug errors (**Figure 37**). 3% felt there had been an increase in drug errors.

Figure 37: Perceived change in the number of drug errors after changing to electronic prescribing systems in neonatal units



Source: GIRFT Clinical Services Questionnaire December 2019

Further information was sought on our deep-dive visits and it was evident that where there was a high level of involvement from neonatal teams, including neonatal pharmacists, in designing the EP system there were some significant benefits. There are significant potential benefits to neonatal safety when the system is specifically adapted to support neonatal prescribing.

There should be a specific focus on rolling out suitable electronic prescribing systems for neonatal care. These require a high level of involvement from neonatology teams and neonatal pharmacists to ensure the design is fit for purpose. Where the existing trust prescribing system is not deemed safe for neonatal use, this must be suitably adapted or an alternative product used.

There is an on ongoing HSIB investigation into weight-based medication errors in paediatric practice, and this may provide further understanding and safety actions to reduce errors and improve electronic prescribing and medicine administration in the neonatal population.[92]

[92] *https://www.hsib.org.uk/documents/295/HSIB_Bulletin_Weight-based_medication_errors_in_children_v04.pdf*

IN PRACTICE

Improving neonatal safety by adapting electronic prescribing systems for neonatal medication and parenteral nutrition

Cambridge University Hospitals NHS Foundation Trust

In October 2014, Cambridge University Hospitals NHS Foundation Trust implemented a trust-wide roll out of Epic (a fully integrated electronic patient record and prescribing system) throughout Addenbrooke's Hospital, Cambridge. Neonatal services were included in this rollout, which allowed an opportunity to review how previous paper-based processes, such as prescribing medication and parenteral nutrition, could be incorporated into an electronic system. Some electronic prescribing systems do not provide enough flexibility to allow the variety of specific neonatal doses to be prescribed and make prescribing of continuous infusions of drugs and IV fluids difficult.

Epic allows specific neonatal prescription builds to be developed and provides decision support for prescribers and nursing staff. Prior to Epic, medical staff often struggled to prescribe drug infusions, such as morphine or inotropes correctly, with differences between the prescribed rate in mL/hr and the required dosing rate, e.g. microgram/kg/min, causing errors. The Epic build has allowed this calculation stage to be removed from prescribers so that whatever concentration of infusion is prescribed, the prescriber selects the dose rate and Epic will automatically calculate the rate in mL/hr that correlates. It allows the prescriber to easily move between different concentrations of the drug for fluid restricted babies without needing to recalculate infusion rates.

Prescribing of gentamicin has improved, with decision support indicating to a prescriber when the last dose was administered, when and what the result of the last gentamicin level taken was, and what the last creatinine value was reported. Development of prescribing order sets has improved prescribing at the admission of a new baby, with prompts to medical staff to prescribe specific emergency drugs and options for pre-set antibiotics to be prescribed at the correct doses and dosing frequency.

Since the initial introduction of Epic further developments have allowed use of barcoding technology to provide scanning of the correct patient, drug and milk feeds during the administration process. Parenteral nutrition is now all ordered electronically via Epic, which has improved timely receipt of parenteral nutrition orders by the pharmacy aseptic team.

As always with a different way of working there is a potential for new types of errors to occur. For example, if the baby's weight is entered incorrectly into Epic, the drug doses could be incorrectly calculated, and medications that are prescribed for a specific duration of therapy may expire on the electronic system when not intentionally discontinued by the prescriber. However, education around regular medication review during daily ward rounds has reduced some of these risks. Overall the implementation of Epic has improved practice around prescribing and administration of medicines to neonatal patients.

Drug and infusion standardisation

Standardisation of drug and infusion practices at a national level is strongly recommended to reduce the risk of errors occurring when babies are transferred between units, increase viability of commercial production of required medication strengths and improve consistency of education and training. Staff in all units should regularly practice preparing common drugs and infusions. In April 2021 a national set of standard infusion concentrations for patients from 2kg body weight upwards was approved by the RCPCH/NPPG Joint Medicine Committee.[93] However, further work will need to be undertaken to develop similar standard infusion concentrations for babies less than 2kg. Following GIRFT discussion with National Patient Safety and Neonatal Paediatric Pharmacy Group (NPPG) leads, development of a national set of neonatal standard infusion concentrations for infants <2kg has been agreed by the RCPCH Joint Medicine Committee in June 2021 and this work has now commenced.

Parenteral nutrition

GIRFT key findings:

- 70% of neonatal units have access to standardised initial and maintenance parenteral nutrition (PN).
- 16% of NICU pharmacists and nearly a third of LNU pharmacists do not have training in PN.

Parenteral nutrition (PN) should also be standardised, ideally across networks (see our separate discussion and recommendations about procurement). GIRFT data shows that currently 70% of units have access to standardised initial and maintenance PN with a further 11% having standardised initial PN only. PN bags should comply with national nutritional recommendations for neonates[94] as well as safety standards including mechanisms to avoid accidental lipid over-infusion as described in the 2017 patient safety alert.[95]

All neonatal units should have access to a pharmacist with competence to provide advice for prescribing and monitoring of PN to complex patients. Currently 16% of NICU pharmacists and nearly a third of LNU pharmacists do not have neonatal PN training (see the *Workforce report* for further details). Neonatal PN training is strongly recommended by the NPPG and the NICE guideline neonatal parenteral nutrition emphasises the importance of the neonatal pharmacist as part of the neonatal parenteral nutrition multidisciplinary team. This is a critical role of the neonatal pharmacist and without this support there is a significant risk of incidents occurring relating to PN provision due to inappropriate PN orders and monitoring.

Neonatal drug calculators

Some networks and several neonatal units have developed simple online clinical drug-dose calculators to aide safe prescribing, particularly in emergency situations, across all hospitals within their network. These calculators allow patient identifiers and weight to be entered and will then produce a full print out of all emergency drugs and common infusions used in neonatal intensive care, with instructions on make up as agreed across that network. They are aids, not prescription charts, and all drugs must be prescribed on the patient's drug chart, with prescribing and administration drug checks completed as normal.

Following changes in Medicines and Healthcare Products Regulatory Authority (MHRA) standards in the last few years regarding medical software/apps potentially needing CE licensing as a medical device, some networks have removed their calculators due to uncertainty regarding the need for CE marking, whilst other networks have felt that it would be unsafe to remove these calculators.

Further clarification regarding clinical calculators was issued by the MHRA in May 2020[96] which suggested that neonatal calculators are not likely to require CE marking. This was confirmed in GIRFT correspondence with the MHRA, which reiterated the revised guidance which is that clinical calculators that contain a few variables and a simple calculation using basic functions which can be easily verified are not categorised as a medical device and therefore do not require a CE mark/UKCA mark. Services will need to collect evidence such as user studies to show that the user can verify the calculation, provide details of the formula used and details of the source research for the calculator.

[93] *https://www.rcpch.ac.uk/resources/standardising-intravenous-infusion-concentrations-children-uk*

[94] *NICE (2020) NG154, Neonatal Parenteral Nutrition*

[95] *NHS Improvement (2017) Patient Safety Alert www.england.nhs.uk/wp-content/uploads/2019/12/Patient_Safety_Alert_-_TPN_in_babies_FINAL.pdf*

[96] *https://www.gov.uk/government/publications/medical-devices-software-applications-apps*

Where trust or network calculators have been developed, these should be checked against the updated MHRA advice and adjustments made to permit these to be used across networks. Existing drug calculators should not be removed until a safer sustainable alternative is in place.

'Smart' pump technology

Infusion pump technology has been developed to prevent over- or under-dosing that could result in serious patient harm or death. Smart infusion pumps have an inbuilt dose error reduction system (DERS) which requires the use of a drug library. The system requires changes to prescribing and administration processes and substantial IT infrastructure to support the integration of smart pump technology. Smart pump libraries work best when standard fixed infusion concentrations are used. Although the aim of smart infusion pumps is to improve patient safety, the technology can introduce new risks and HSIB have produced a rigorous report on the use of these technologies, with key advice and safety recommendations for their general implementation.[97] There is currently limited evidence for reduction in errors in the neonatal population, although GIRFT came across examples of trusts, e.g., Nottingham University Hospitals NHS Trust, who felt this technology had been beneficial.

Smart pump technology is more likely to reduce medication errors in neonates compared to other populations but there is currently a paucity of evidence to show this. National Patient Safety leads and Neonatal and Paediatric Pharmacy Group leads strongly support the recommendation for trusts to implement this technology and audit the impact on medication errors in neonates. Ideally this should be implemented as a 'closed loop administration system' using pre-made infusions, e-prescribing, barcode scanning and bi-directional pump technology. This allows infusion parameters to be sent wirelessly from the electronic patient record (EPR) to prepopulate the smart infusion pump and infusion data sent wirelessly back to the EPR.

Pre-made medications

Pharmacy aseptic services can prepare a large variety of medications in controlled sterile environments, reducing drug contamination and drug errors as well as releasing nursing time taken to make up drugs in the neonatal unit. There are very few medications being pre-made for use in a pharmacy for neonatal units (**Table 5**) and reasons given for this include resource costs to implement and the lack of aseptic services/space available. Where these services do exist however, GIRFT found that neonatal services really valued and appreciated them.

Table 5: Percentage of neonatal units where common intravenous infusions and drugs are made up in pharmacy dispensaries

	Cefotaxime	Penicillin	Gentamicin	Morphine	Inotropes
All units	6%	4%	4%	10%	7%
NICUs	9%	7%	9%	19%	12%

Source: GIRFT Clinical Services Questionnaire December 2019

[97] *https://www.hsib.org.uk/investigations-cases/smart-pumps/*

IN PRACTICE

Reducing medication errors by using a pre-made intubation drugs toolkit as part of Project NIK

University Hospital Southampton NHS Foundation Trust

The process of pre-medication for elective intubation of a neonate is time critical and complex. The prescribing and drug preparation of medications commonly used for intubation takes a significant amount of time and can be prone to miscalculation due to time pressures on the clinical team. The team at Princess Anne Hospital has designed a toolkit to provide teams with training resources, including human factors training, alongside use of pre-made intubation drugs to address this issue. This included:

- A checklist and standardised multidisciplinary pre-intubation huddle.
- A pack of pre-made intubation medications (atropine, suxamethonium, fentanyl).
- Human factors training.

Pre-made intubation medications, called the Neonatal Intubation Kit (NIK) were made up by the Centralised Intravenous Additive Service (CIVAS) in pharmacy. These prefilled syringes contain a standard dilution of each drug which can be used across a wide weight range (<500g to 5Kg using 11 dose bands). Importantly, the volume of each drug (atropine, suxamethonium and fentanyl) required at any given dose band is the same, reducing the risk of errors. Each batch has a seven-day shelf life from the date of production.

A review of cases in calendar year 2018 alongside a qualitative survey of practice post-implementation demonstrated no significant complications during the prescribing, preparation and administration of the drugs. Time to drug administration was significantly reduced and no medication errors were identified during this period.

IN PRACTICE

Improving drug safety by using standardised concentrations of common drug infusions

Guy's and St Thomas' NHS Foundation Trust

For over a decade the neonatal unit at St Thomas' Hospital has used standard concentrations for some drug infusions used in their neonatal unit (morphine, milrinone, clonidine, dinoprostone and vancomycin). Batch-manufactured pre-filled syringes (PFS) are produced in-house in the manufacturing unit at the acute trust.

The benefits of pre-filled syringes have been as follows:

1. Higher quality product with reduced drug concentration variability and improved sterility, permitting longer shelf life (several weeks/months).
2. Reduction in drug errors. For example:
   - prescribing is easier for doctors who only need to select the most appropriate strength syringe from the options available and no complex calculations for individualised prescriptions for every baby;
   - nurses no longer need to make up complex infusions on the ward; and
   - smart pumps are programmed in line with standard concentration syringes. The pumps are programmed to match the strengths of the syringes available, so extra safety parameters are in place to minimise risk of errors with individualised smart pump programming. Minimum and maximum doses are set with hard and soft limits.
3. Reduced risk of infection. Due to sterility of manufacturing environment, once attached to a patient, these infusions can run for 48 hours compared to 24 hours for infusions that have been made up in a less sterile ward environment. IV lines are manipulated less frequently.
4. Storage is simplified. Readily available syringes are stored on the neonatal unit in a ready-to-use fashion (with exception of vancomycin PFS, which are manufactured on a 'when required' basis). Morphine, milrinone and clonidine are stored at room temperature, whilst dinoprostone is refrigerated.

IN PRACTICE

Benefits of pre-made medication infusions

Liverpool Womens NHS Foundation Trust

Liverpool Women's Hospital currently use four pre-made medication infusions, not including PN and lipid. These are morphine (all strengths), suxamethonium, teicoplanin and amphotericin. Their use has increased and decreased over recent years, depending upon contracts and availability.

The benefits outweigh the costs, as the time taken to administer these frequently used or emergency drugs are significantly decreased, as is the margin for error. The only drawbacks are the shorter expiration date, which may result in wastage if the drug is not one of high usage, and the risks of unfamiliarity with re-constitution processes if the pre-made syringes run out.

There is a national drive to transform NHS pharmacy aseptic services in England[98] to improve access to ready-to-use medication and reduce the need for manipulation of medication outside pharmacy sterile controlled settings. This will improve safety as well as releasing nursing time back to caring for babies. Opportunities to reduce local drug preparation in neonatal units with this expanded service must be sought at regional and national level.

Neonatal assessment and screening procedures

Several assessment and screening tools are commonly used in neonatal care to improve clinical safety, some of which are also part of national screening programmes. We include data and information from deep-dive visits on screening for jaundice and oxygen saturation screening. The importance of early identification and management of common neonatal conditions such as jaundice, hypoglycaemia and infection, as well as comprehensive screening procedures including NIPE (newborn and infant physical examination), newborn infant check, hearing and ROP (retinopathy of prematurity) screening, are included in the litigation section of this report.

GIRFT key findings:

- Only 60% of neonatal units and 35% of community teams have good access to transcutaneous bilirubinometers.
- 48% of units were performing pulse oximetry screening for all infants with a further 28% performing targeted screening.

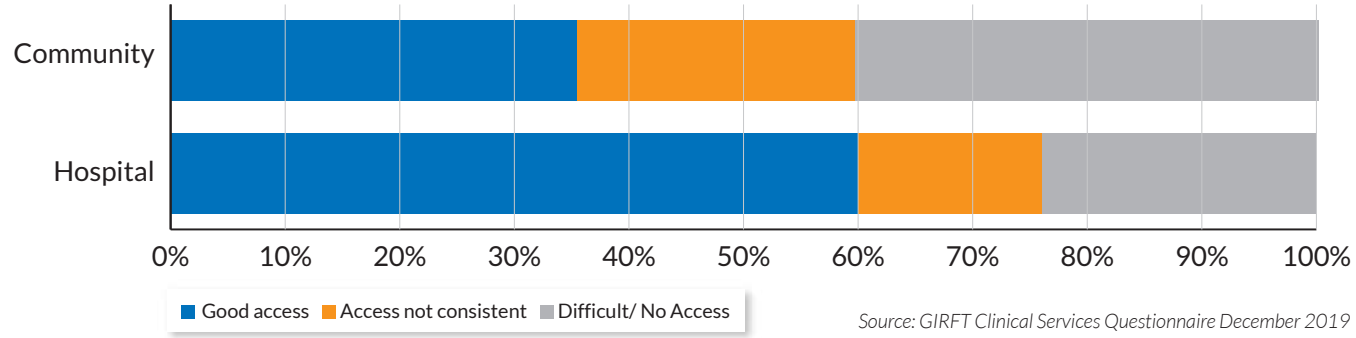
Assessment for neonatal jaundice

NICE guidance on neonatal jaundice[99] was introduced in 2010 and updated in 2016. It recommends the use of objective methods of transcutaneous bilirubinometry (TcB) and total serum bilirubin (TSB) measurements, because visual assessment of jaundice levels has been shown to be unreliable, particularly for babies with more richly pigmented skin. TcB has been shown to correlate with TSB levels, and although it should not be used as a standalone screening device for diagnosis of jaundice, it can be used in conjunction with assessment of risk factors, clinical examination, and laboratory measurements. TcB is non-invasive and therefore prevents the need for a painful procedure in many infants, provides instant results and can be readily used in the community. It is therefore disappointing to see that only 60% of neonatal units had good access to TcB in hospital and 35% in the community (**Figure 38**). GIRFT visits suggested that cost was a factor. It is strongly recommended that all hospital and community services should have access to TcB as recommended by NICE.

[98] *NHS Improvement (2019) The Future of Pharmacy Aseptic Services in England https://www.sps.nhs.uk/wp-content/uploads/2019/02/The-Future-of-Pharmacy-Aseptic-Services-in-England-270219.pdf*

[99] *NICE (2010) CG98 Jaundice in newborn babies under 28 days https://www.nice.org.uk/guidance/cg98*

Figure 38: Percentage of neonatal units with access to transcutaneous bilirubinometers in hospital and community services

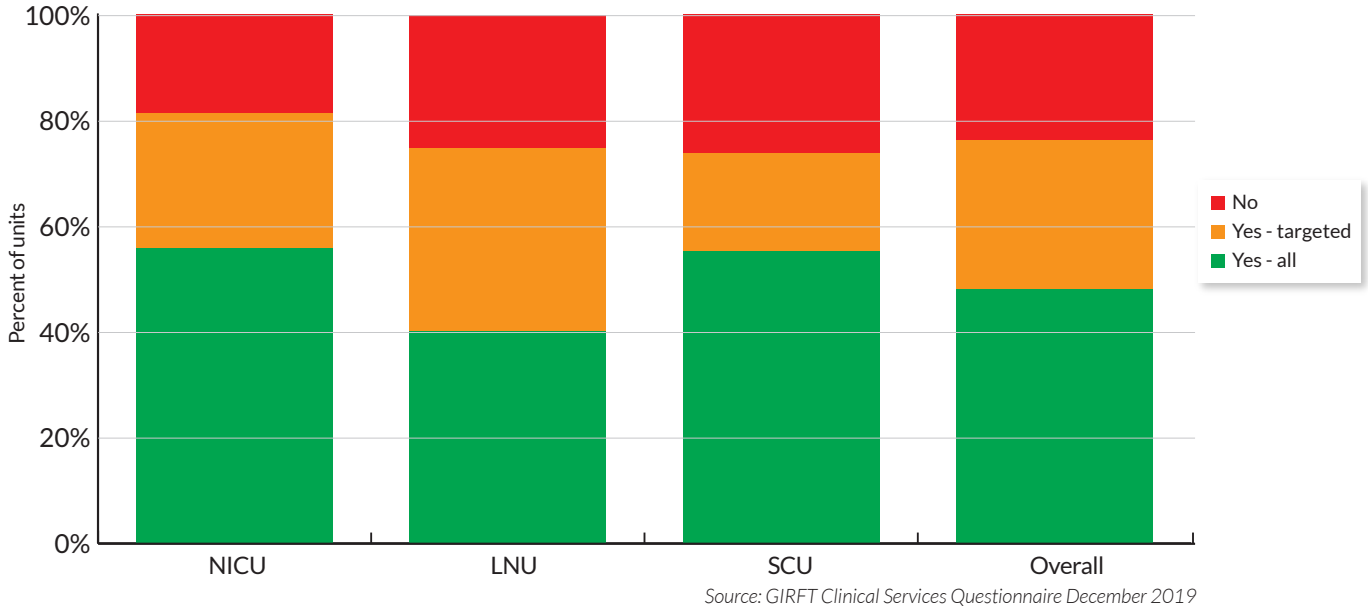


Source: GIRFT Clinical Services Questionnaire December 2019

Pulse oximetry screening

Pulse oximetry screening (POS) has been shown to increase detection of critical congenital heart disease from around 50-70% to 92%. Importantly, there is also evidence for earlier detection and initiation of treatment for other potentially life-threatening conditions including sepsis, persistent pulmonary hypertension of the newborn (PPHN) and pneumonia.[100, 101, 102] The requirements for recommendation as a part of national screening are very stringent and this has not been implemented in the UK yet with results of ongoing research awaited before further evaluation by the UK National Screening Committee (UK NSC). However, routine screening has been adopted in many other high-income countries and data from the United States shows a 33% reduction in mortality for critical congenital heart disease following the introduction of POS on a 'state by state' basis[104] and there is also data to suggest reduced morbidity from non-fatal collapse.[105] **Figure 39** shows data on units performing universal screening, by designation.

Figure 39: Use of POS screening, by unit designation



Source: GIRFT Clinical Services Questionnaire December 2019

[100] *Thangaratinam S, Brown K, Zamora J, Khan KS, Ewer AK. (2012) Pulse oximetry screening for critical congenital heart defects in asymptomatic newborn babies: a systematic review and meta-analysis. Lancet.*

[101] *Plana MN, Zamora J, Suresh G, et al. (2018) Pulse oximetry screening for critical congenital heart defects. Cochrane Database Syst Rev.*

[102] *Ewer AK, Furmston AT, Middleton LJ et al. (2012) Pulse oximetry as a screening test for congenital heart defects in newborn infants: a test accuracy study with evaluation of acceptability and cost-effectiveness. Health Technology Assessment https://www.ncbi.nlm.nih.gov/books/NBK84052/pdf/Bookshelf_NBK84052.pdf*

[103] *Discussed in: https://www.birmingham.ac.uk/documents/college-mds/metabolism-systems/pulse-ox/1-page-summary-of-recommendation-2019.pdf*

[104] *Abouk R, Grosse SD, Ailes EC, Oster ME. (2017) Association of US state implementation of newborn screening policies for critical congenital heart disease with early infant cardiac deaths. JAMA.*

[105] *de-Wahl Granelli A, Wennergren M, Sandberg K, et al, (2009) Impact of pulse oximetry screening on the detection of duct dependent congenital heart disease: a Swedish prospective screening study in 39821 newborns, BMJ*

Further data was collected by Prof Ewer and colleagues in 2020 demonstrating a slight increase to 51% neonatal units undertaking universal POS screening in 2020, with marked variation in regional uptake (levels above 80% in the Northern and North West networks, and levels below 50% in East of England, South West, Thames Valley & Wessex and Kent, Surrey & Sussex networks).[106] Since this survey GIRFT is aware that a number of whole networks are now working with maternity colleagues to instigate screening across regions.

IN PRACTICE

The implementation of pulse oximetry screening

Thames Valley and Wessex Neonatal ODN[107]

The Thames Valley and Wessex Neonatal ODN consists of 14 neonatal units. In 2020, only 2 out of the 14 units were undertaking POS for all newborns born in their hospitals. This is one of the key priorities and patient safety initiatives of the neonatal ODN to increase the identification rate of critical congenital heart disease, but also to identify the unwell newborn with non-cardiac causes of low/borderline saturations.

The network embarked on their journey for the implementation of POS in 2020. A stakeholder webinar was held in September 2020 and with the engagement of nurses, midwives and clinicians, the implementation of POS widely across the network was agreed. The project is being led by a Thames Valley and Wessex neonatal transformation fellow, having developed a range of materials including a network guideline to support the implementation of POS.

The guideline package includes:

- Access to the POS webinar held September 2020, which includes presentation of evidence by Professor A. Ewer and models of implementation.
- Screening pathways for babies born in hospital, Maternity Led Units (MLU) and at home.
- Investigations of babies who test positive.
- A parent information leaflet.
- Information guidance for health care professionals performing the screening.
- A video education training package.

Following the development of the guideline package, a network implementation team (consisting of the neonatal transformation fellow, the network project manager, and the network education leads), have been supporting local units with a series of implementation and training events with each organisation, including support for acquisition of pulse oximeters. The uptake of POS has been actively encouraged through network clinical forums, patient safety groups, and LMS clinical forums. There has also been engagement with the Congenital Heart Disease network, discussing the possible implications of the implementation of POS on cardiology services, ultimately gaining their support.

The lack of recommendation from the UK National Screening Committee for the implementation of POS nationally led to some challenges in the implementation process, causing dichotomy in progressing with POS in some of their organisations. Funding of equipment has been another challenge for some organisations. Tiny Tickers, the charity organisation supporting neonatal POS, was contacted at network level, and local organisations were signposted to apply for equipment through them. Some of their organisations have successfully acquired equipment through this route. The team have come a long way in their journey, with many of their organisations keen to implement POS and many well underway with the implementation process. Although there is still a considerable amount of work to be done to successfully implement POS across the Thames Valley and Wessex Network, they strive for clinical excellence and aim to continue the journey in ensuring every baby born in their network undergoes POS.

[106] *Brown S, Liyanage S, Mikrou P, Singh A, Ewer AK. (2020) Newborn pulse oximetry screening in the UK: a 2020 survey. Lancet*

[107] *Further information available at: https://southodns.nhs.uk/wp-content/uploads/2021/01/TVW-Neonatal-ODN-Pulse-Oximetry-Screening-Guideline-Final-V2-March-2021.pdf*

There is evidence of growing inequity in access to universal POS across England with significant regional variation. There are also concerns expressed by British Congenital Cardiac Association (BCCA), that perception of cyanosis is not uniform amongst ethnic groups and that detecting cyanosis purely by eye may disadvantage certain ethnic groups, including Asian and Black babies. In addition, there is marked variation in prenatal detection rates for congenital heart disease across the country (34-65%) which may compound inequities in early diagnosis of congenital heart disease caused by patchy universal POS.[108] In the 2020 survey, 75 (78%) of the 96 neonatal units already undertaking universal screening felt that screening did not increase the number of unnecessary investigations, and ten (10%) neonatal units felt that any small increase was justified and off-set by the benefits of identifying considerable cardiac and non-cardiac pathology.

Given the current situation, it is strongly recommended that neonatal ODNs and LMSs/LMNSs should review the evidence and work together to support roll out of POS across all units. The UK NSC will review further evidence in due course and is strongly encouraged to reconsider inclusion of pulse oximetry screening as part of the national screening programme, considering both the increasing number of neonatal units already undertaking universal screening and the resultant significant regional inequity. It is evident from the 2019 NSC consultation that a decision to support national screening would be strongly welcomed by many patient and professional groups including BCCA and BAPM.[109, 110]

Reducing the impact of litigation

The GIRFT neonatology review has examined the impact and causes of litigation within neonatology with a view to reducing the frequency of litigation and reducing the incidents that lead to it. It is important for clinical staff to have the opportunity to learn from claims, complaints, incident reporting, HSIB investigations, relevant national reports and inquests in order to reduce harm to patients and reduce costs of both litigation and management of complications resulting from such incidents. [111, 112]

The claims details provided by NHS Resolution and trusts are not always robust enough to distinguish fully from which part of a patient's journey a claim has arisen. Clinical negligence claims related to neonatology services previously were attributed to either maternity, paediatrics or intensive care services. NHS Resolution is committed to driving improvements in both maternity and neonatal services and from 2020 onwards, claims can be attributed to neonatology directly.

We sourced data from NHS Resolution on all medical negligence claims notified between April 2015 and April 2020. We identified all claims involving care of babies in neonatal units. After expert review of available incident details, we identified 105 claims directly related to care in neonatal units (**Table 6**). We identified a further 309 claims related to the care provided by other services to neonatal patients (babies aged under 28 days) (**Table 7**). A total of 414 claims are related to the care of all babies admitted to neonatal units or neonates (aged <28 days) cared for in other services. The median lag between claim notification to NHS Resolution and reported incident date is three years (IQR 1-6 years), although this lag can be many years due to the extended notification period allowed for these patients.

Although we made every effort to produce the most accurate data, the number of claims is likely to be under-represented due to the absence of a specific category for neonatology before 2020 and the limitations of the clinical details of the data available. However, the data presented here provides national litigation data for neonatal patients for the first time.

Variation in average litigation costs

The number of claims related to neonatology services, per year, has been stable over the last five years and is low, at 19 to 23 per year. The median claim costs are high at £76,500 compared to a median of £62,677 for all claims notified to NHS Resolution assigned to any speciality but slightly lower than median claim costs for obstetrics claims (£82,000). Average total costs per financial year across the five-year period are £51.9m (range £29.5m – £76.7m) with 18 claims having total costs greater than £10m each. The variation between financial years reflects the variation in high-cost claims with no overall trend.

[108] *NICOR (2020) National congenital heart disease audit (NCHDA) 2020: Summary report (2018/19 data) https://www.hqip.org.uk/resource/congenital-heart-disease-2020-summary-report/*

[109] *https://www.birmingham.ac.uk/documents/college-mds/metabolism-systems/pulse-ox/po-uk-nsc-coversheet-consultation-responses-2019-clean.pdf*

[110] *BAPM urges UK NSC to reconsider pulseox screening recommendation, https://www.bapm.org/articles/45-bapm-urges-uknsc-to-reconsider-pulseox-screening-recommendation*

[111] *Ockenden D (2020) Emerging Findings and Recommendations from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust https://www.gov.uk/government/publications/ockenden-review-of-maternity-services-at-shrewsbury-and-telford-hospital-nhs-trust*

[112] *Kirkup B, (2015) The Report of the Morecambe Bay Investigation https://www.gov.uk/government/publications/morecambe-bay-investigation-report*

Table 6: Volume and cost of 105 medical negligence claims related to neonatology services notified to NHS Resolution 2015/16 to 2019/20

Notification year	No. of claims	% change in no. of claims	Total costs (£ million)	% change in total costs
2015/16	19		29.5	
2016/17	22	16%	76.7	160%
2017/18	21	-5%	44.9	-41%
2018/19	23	10%	63.8	42%
2019/20	20	-13%	44.7	-30%
Total	**105**		**259.6**	

Further review of claims related to the care of neonatal patients under other specialities identified a cohort of 309 claims; the majority of the claims, 59% (181) were coded under obstetrics. The total claim costs are detailed in **Table 7**; median claim costs are higher £150,000 (IQR £0.5 - £5.3m) and likely reflect claims for severe brain injury following complications at the time of birth and/or delayed diagnosis of hypoglycaemia, jaundice or infection. Average total costs per financial year, across the five-year period are £166.8m (range £110m-133.8m). Costs were particularly high in 2018/19, predominantly due to a larger number of high-value claims.

Table 7: Volume and cost of 309 medical negligence claims related to specialities involved in the care of neonatal patients notified to NHS Resolution 2015/16 to 2019/20

Notification year	No. of claims	% change in no. of claims	Total costs (£ million)	% change in total costs
2015/16	65		110.1	
2016/17	55	-15%	140.0	27%
2017/18	66	20%	157.2	12%
2018/19	71	8%	285.3	81%
2019/20	52	-27%	133.8	-53%
Total	**309**		**826.4**	

Claims trends and causes

Using the NHS Resolution data, common causes for litigation in our cohort were identified. More than one cause can be assigned to each claim depending on the nature of the claim described. The most common cause assigned to claims are failure/delay in treatment (31%) and failure/delay in diagnosis (19%), which is consistent with claims in other specialities.

High-value claims related to neonatology services

There were 18 out of 105 claims identified with total claim costs greater than £10m each. There were 14 claims which identified brain injury associated with clinical negligence, which reflects the high value of the claim. Reviewing the incident details identified the following clinical features:

- overventilation and hypocarbia in one third of high claims' cases;
- failure to diagnose/treat infection in one quarter of high claims' cases;
- failure to diagnose/treat jaundice in one sixth of high claims' cases.

It should be noted that a large number of high-cost claims allocated to maternity services, particularly those involving hypoglycaemia, infection and resuscitation may also involve neonatology services to a greater or lesser extent.

Common themes

Further review of all 414 claims involving neonates identified common themes to learn from and improve care of neonatal patients, in addition to reducing the financial costs associated with clinical negligence. These are summarised in **Table 8**.

Table 8: Common themes for neonatal claims

	No Claims	Cost/claim	Cost/claim
Hypoglycaemia	26	£8.9m	£230m
Infection	37	£3.7m	£137m
Resuscitation	21	£5.2m	£109m
Jaundice	20	£5.5m	£109m
Overventilation/hypocarbia	6	£8.9m	£53m
Newborn screening and congenital anomalies	75	£0.4m	£32.8m
Medication and fluids	10	£1.9m	£19m
Equipment causing injury	34	£0.4m	£15.2m

Hypoglycaemia

Neonatal hypoglycaemia can cause severe long-term neurodevelopmental harm to the baby, as well as significant financial cost to the NHS through high litigation costs, with total claim costs at £230m. 18 claims had total claim costs greater than £10m. Reviewing the claims, areas of clinical negligence include delay in diagnosis and/or treatment (more than half of cases), feeding practices in neonates (12% of claims), identification of high-risk babies (12% of claims) and neonatal care leading to hypoglycaemia (also 12% of claims). 77% of claims cited brain injury as an outcome.

Learning from high litigation costs associated with hypoglycaemia has been highlighted by NHS Improvement's Patient Safety Programme.[113] All neonatal and maternity units have clearly identified pathways for managing neonatal hypoglycaemia as part of the Avoiding Term Admissions into Neonatal units (ATAIN) programme (Maternity Incentive Scheme Safety Action 3).[114] Support for clinicians is provided by the BAPM Framework for Practice for the Identification and Management of Neonatal Hypoglycaemia in the Full Term Infant, which addresses variation in practices and promotes safer practices that avoid unnecessary separation of mother and baby.[115] NICE have also issued guidance on managing diabetes in pregnancy.[116]

Infection

Of the 37 claims related to early and late onset neonatal infection, eight claims had total claim costs greater than £10m. The most common causes identified were: delayed/failure of diagnosis (more than half of cases), negligence in infection control and prevention, and delayed/failure of treatment including delay in administering antibiotics. The commonest organisms cited (where detail was available) were: Group B streptococcus (GBS) (one fifth of cases); MRSA and herpes simplex virus (HSV). 30% of claims identified an outcome of death and 16% of claims identified brain injury.

HSIB published a national learning report in July 2020,[117] highlighting findings and recommendations from their investigations in relation to GBS and NICE guidance (NG195) on neonatal infection, antibiotics for prevention and treatment

[113] *Hawdon JM, Beer J, Sharp D On behalf of NHS Improvement Patient Safety Programme (2017) 'Reducing Term Admissions to Neonatal Units' Neonatal hypoglycaemia: learning from claims, Archives of Disease in Childhood - Fetal and Neonatal Edition*

[114] *NHS Resolution (2021) Maternity incentive scheme – year three https://resolution.nhs.uk/wp-content/uploads/2021/02/Maternity-Incentive-Scheme-year-three-final-01022021.pdf*

[115] *BAPM, Identification and Management of Neonatal Hypoglycaemia in the Full Term Infant (2017): A BAPM Framework for Practice, https://www.bapm.org/resources/40-identification-and-management-of-neonatal-hypoglycaemia-in-the-full-term-infant-2017*

[116] *NICE (2015) NG3 Diabetes in pregnancy: management from preconception to the postnatal period*

[117] *Healthcare Safety Investigation Branch (2020) National Learning Report Severe brain injury, early neonatal death and intrapartum stillbirth associated with group B streptococcus infection. https://www.hsib.org.uk/documents/229/hsib-national-learning-report-group-b-strep.pdf*

was updated in April 2021.[118] In relation to the claims identified, there are new recommendations for identifying at-risk neonates, management of GBS colonisation during and after pregnancy and when to consider lumbar puncture. The Kaiser Permanente (K-P) neonatal sepsis calculator is also included as an alternative to NICE guidance to calculate the risk of early-onset sepsis in infants. This calculator is felt to reduce the number of babies given antibiotics. However, balancing recognition/treatment of possible infection with preventing unnecessary use of antibiotics is a challenge and units using the K-P calculator must audit outcomes. Some comparisons have already been published in the UK.[119, 120]

Critical care patients are at high risk of healthcare acquired infections (HCAIs) with the additional challenge of multidrug resistance. Approximately 15% of UK neonatal ICUs have been investigated for recent infection prevention and control (IPC) issue and 12% per year temporarily closed for this reason, with neonatal surgical units being particularly vulnerable.[121] Eight claims in our cohort were identified with clinical negligence in IPC. Late-onset bloodstream infection and central line associated bloodstream infection (CLABSI) data is presented via NNAP,[122] with recommendations for improving practice including optimising evidence-based infection reduction strategies and comparing and sharing best practice between units with high and low infection rates across the whole multidisciplinary team. The Infection in Critical Care Quality Improvement Programme (ICCQIP) works across neonatal, paediatric and adult patients and aims to reduce infection rates, focusing initially on blood stream infections.[123]

Resuscitation

These claims were predominantly related to airway and breathing management at resuscitation. The importance of good quality newborn resuscitation has been recognised by NHS Resolution[124, 125] and is included in Maternity Incentive Scheme (Safety Action 8).[126] There are excellent resources for managing the difficult airway outlined in a BAPM Framework for Practice.[127]

These claims emphasise the need for ongoing updating and maintenance of key resuscitation skills and emergency practical procedures, with specific recommendations and actions outlined in this report (see clinical recommendations).

Neonatal jaundice

Of the 20 claims, 18 specified delay in diagnosis and/or treatment with insufficient details to determine the cause of clinical negligence in the remainder. There were 12 claims that specified brain injury as a clinical outcome.

A recent study examined claims involving neonatal jaundice notified between 2001-2011.[128] They identified 20 claims with a cost at £150m. The main challenge for healthcare professionals lay in the identification of the rare baby whose bilirubin level is rising rapidly to levels that are potentially neurotoxic. The key messages that emerged were the importance of ethnicity, family history, continued inappropriate use of sunlight as therapy and delay in measuring bilirubin levels in babies who are recognised to have jaundice.

Treatment therapy includes exchange transfusion for the most severe cases and where antenatal risk factors suggest there is a high risk of postnatal exchange transfusion, neonatal ODNs and maternity networks should have clearly agreed pathways for antenatal transfer to ensure delivery at a site where the neonatal unit has appropriate staffing and expertise on site ***at all times*** to undertake this procedure. Neonatal networks should also have very clear postnatal pathways for managing these babies as well as ensuring regular simulation training is in place to train staff to perform this procedure.

[118] *NICE (2021) NG195 Neonatal infection: antibiotics for prevention and treatment https://www.nice.org.uk/guidance/ng195*

[119] *Goel N, Shrestha S, Smith R, et al, (2020) Screening for early onset neonatal sepsis: NICE guidance-based practice versus projected application of the Kaiser Permanente sepsis risk calculator in the UK population, Arch Dis Child Fetal Neonatal Ed*

[120] *Morris R, Jones S, Banerjee S, et al. (2020) Comparison of the management recommendations of the Kaiser Permanente neonatal early-onset sepsis risk calculator (SRC) with NICE guideline CG149 in infants ≥34 weeks' gestation who developed early-onset sepsis. Arch Dis Child Fetal Neonatal Ed*

[121] *Francis, S, Khan, H, Sharland, M. (2011) Infection control in UK neonatal units: the greater impact in surgical units. Arch Dis Child Fetal Neonatal Ed*

[122] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data*

[123] *ICCQIP Collaboration (2016) A national Infection in Critical Care Quality Improvement Programme for England: A survey of stakeholder priorities and preferences. J Intensive Care Soc.*

[124] *NHS Resolution (2019) A summary of: The Early Notification scheme progress report, 2019. https://resolution.nhs.uk/wp-content/uploads/2019/10/NHS-Resolution_Early-Notification-Scheme-Summary-Report.pdf*

[125] *Magro M, NHS Resolution (2017) Five years of cerebral palsy claims https://resolution.nhs.uk/wp-content/uploads/2017/09/Five-years-of-cerebral-palsy-claims_A-thematic-review-of-NHS-Resolution-data.pdf*

[126] *NHS Resolution (2021) Maternity incentive scheme – year three https://resolution.nhs.uk/wp-content/uploads/2021/02/Maternity-Incentive-Scheme-year-three-final-01022021.pdf*

[127] *BAPM (2020) Managing the Difficult Airway in the Neonate https://hubble-live-assets.s3.amazonaws.com/bapm/attachment/file/353/DA_framework_final_October_2020.docx.pdf*

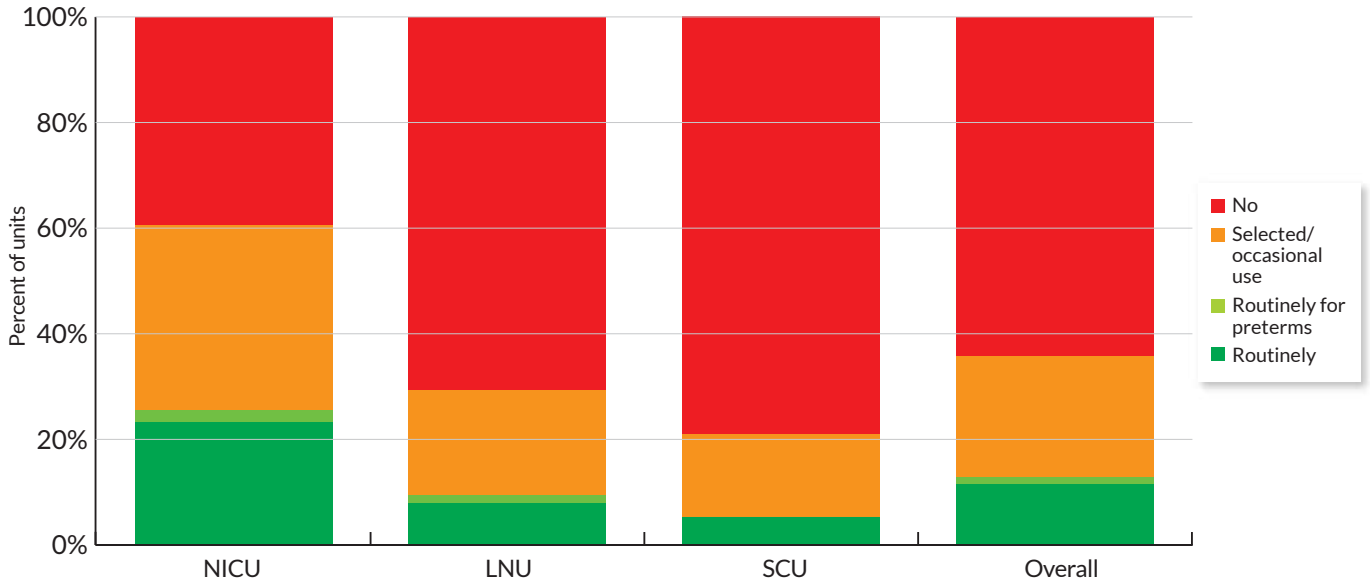
[128] *Rennie JM, Beer J, Upton M. (2019) Learning from claims: hyperbilirubinaemia and kernicterus. Arch Dis Child Fetal Neonatal Ed*

Overventilation and hypocarbia

Of the six claims, five resulted in high claims value of over £10m each (average total claim costs £8.9m). NICE guidance recommends more frequent use of non-invasive respiratory support as first line therapy to reduce the need for mechanical ventilation,[129] and the use of synchronised volume targeted ventilation will also reduce the risk of overventilation and hypocarbia (see separate discussion and recommendations about improving clinical aspects of care from page 60-63 onwards).

Monitoring carbon dioxide (CO2) levels remains technically challenging in preterm infants. Our data showed that 97% neonatal units checked end-tidal CO2 detection following intubation, usually using colorimetric devices. However, currently, a low number of units use either end-tidal or transcutaneous CO2 monitoring for continuous monitoring of ventilated patients (**Figure 40**). It is hoped that improvements in technology will encourage more consistent use of these devices in future.

Figure 40: Percentage neonatal units using continuous CO2 monitoring in ventilated patients



Source: GIRFT Clinical Services Questionnaire December 2019

Newborn screening and identification of congenital anomalies

The Newborn Infant Physical Examination (NIPE) screening programme screens babies after birth for common congenital anomalies of the eyes, heart, hips or testes with key national screening pathways and there are clear safety processes described to follow up anomalous results and manage safety incidents.[130, 131] Of the 75 claims, 28 were related to delayed diagnosis and/or treatment of developmental dysplasia of the hip; 14% of these claims specified negligence in failure to arrange follow-up ultrasound scans. Many European countries have introduced screening programmes based on universal ultrasound which not only reduced late diagnosis but also overall cost of treatment (see GIRFT paediatric trauma and orthopaedics report).

Nine percent of claims specified delayed diagnosis of congenital heart disease (see pulse oximetry screening earlier in this chapter). The remainder of the claims were related to delayed diagnosis of anorectal malformations including imperforate anus (15%), cleft palate (13%) and spinal anomalies including spina bifida (9%).

Anorectal anomalies may be more likely to be missed when meconium is passed through a fistula and local training for the NIPE check should ensure this issue is highlighted. Regional NIPE training programmes should include specific mention of this issue.

[129] *NICE (2019) NG124 Specialist neonatal respiratory care for babies born preterm*

[130] *https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-screening-standards*

[131] *Woodland J. Public Health England. (2017) Managing Safety Incidents in NHS Screening Programmes https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/672737/Managing_safety_incidents_in_National_screening_programmes.pdf*

There is variation in practice regarding management of signs consistent with potential spinal cord anomalies in the newborn period. Network-wide protocols for initial management and referral pathways should be agreed jointly by paediatric neurosurgical services/networks and neonatal ODNs as part of a wider collaboration between the two networks with regards to neurosurgical pathways.

Fewer than five claims specified a delay in diagnosing hearing loss, for which there is also a national screening programme. Further claims relate to screening delay for diagnosis and treatment of retinopathy of prematurity (ROP) with average total claim costs at £1.2m. NNAP identified 3.9% of eligible babies were either not screened, or not screened on time.[132] GIRFT endorses NNAP recommendations for trusts to have systems to ensure babies requiring ROP screening are accurately identified, as per the joint RCPCH guidance in collaboration with BAPM and the Royal College of Ophthalmology,[133] and that safety systems for appropriate ROP screening are in place.

Medication and fluids

Of the ten claims, some describe a medication overdose or incorrect dose, others describe medication delays or omission and fluid and electrolytes errors. Actions to improve drug safety are included earlier in this chapter.

Equipment causing injury

The most common types of equipment involved were umbilical central lines (11 claims), arterial lines (five claims), peripheral venous cannulae (five claims) and ventilatory support. The injuries/outcomes most commonly cited were skin injury (11 claims), limb injury including amputation of hands or digits (nine claims). Other injuries included peritoneal injuries such as bowel perforation, liver abscess and intraperitoneal extravasation, pericardial effusion or cardiac tamponade. Nine claims had death as an outcome.

All units should be aware of the potential for significant complications associated with use of central venous catheters and should follow the recommendations in the relevant BAPM Framework for Practice.[134]

Summary of findings and actions

Many agencies have taken an active interest in promoting safety and reducing litigation claims in neonatology. Actions and recommendations in this report promote earlier identification and prompt management of common neonatal conditions such as hypoglycaemia, infection, and jaundice which are associated with higher risk of harm, as well as highlighting drug safety and promoting the importance of comprehensive neonatal screening procedures to reduce patient harm and litigation costs.

We recommend frank and honest engagement with parents at the earliest possible opportunity following identification of an incident or complaint, to listen to their case and explore their perceptions and understanding. This will not negate the formal process of case review.

Clinicians and trust management should discuss with the legal department or claims handler, the claims submitted to NHS Resolution in the data set, to confirm correct coding to neonatology. Claims for neonates can occur in neonatology, paediatrics (including paediatric subspecialties), paediatric intensive care or maternity. All claims for infants <28 days old at the time of the incident, should be reviewed by the respective teams to ensure accurate assignment of the claim to the correct team. The teams should also inform NHS Resolution of any claims which are not coded correctly to the appropriate speciality. Following this, meaningful review of the claims can occur within the departments and the wider organisation, to identify and share areas for learning, improvement, and action for patient safety.

[132] *RCPCH (2020) National Neonatal Audit Programme (NNAP) 2020 annual report on 2019 data www.rcpch.ac.uk/sites/default/files/2020-11/nnap_report_2020_final_pdf2.pdf*

[133] *Royal College of Paediatrics and Child Health (2021) UK Screening of Retinopathy of Prematurity Guideline*

[134] *BAPM (2018) Use of central venous catheters in neonates (revised 2018) https://www.bapm.org/resources/10-use-of-central-venous-catheters-in-neonates-revised-2018*

Recommendations to strengthen clinical governance and safety, and reduce litigation

Recommendation	Actions	Owners	Timescale from date of publication
11. Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**a** Implement a clear governance and communications structure from neonatal ODNs to specialised commissioning.	Neonatal ODNs, regional specialised commissioning teams	6 – 12 months
	b Review neonatal risk registers quarterly at both network and trust level. There should be clearly outlined processes for escalation of risk within the trust, from trust to network and from network to region.	Neonatal ODNs, regional specialised commissioning teams, trusts	6 – 12 months
	c Coordinate an approach to maternity and neonatal governance at both local and regional level. Whilst recognising that particular issues may require more in depth focus at specialty level, there must be appropriate overarching structures for both governance and mortality review.	LMSs/LMNSs, neonatal ODNs, trusts, trust maternity and neonatal safety champions	12 – 18 months
	d Standardise the neonatal death review process within the network. All deaths should be reviewed at network level; there should be LMS/maternity representation and network oversight of local trust mortality review. PMRT outputs and the networks should be involved in neonatal Child Death Overview Panels to provide a more robust mortality review framework.	Trusts, neonatal ODNs, LMS/LMNS/ CDOP panels	12 months
12. Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**a** Develop a national set of neonatal standard infusion concentrations to reduce the risk of errors occurring when babies are transferred between units; increase viability of commercial production of the required medication strengths; and improve consistency for education and training.	National Patient Safety Programme, RCPCH Joint Medicine Committee	1 – 2 years
	b Increase the use of ready-to-use standardised concentrations of drugs and infusions, prepared in pharmacy aseptic services or by external suppliers, and reduce local drug preparation in neonatal units.	Neonatal ODNs, trusts, regional perinatal safety groups, NPPG, NHS pharmacy aseptic services	2 – 5 years
	c Adjust, where applicable, trust or network-developed drug calculators to ensure they are updated against MHRA advice and can be used across networks. Existing drug calculators should not be removed until a safer sustainable alternative is in place.	Neonatal ODNs and trusts	6 – 12 months
	d Ensure standardised parenteral nutrition (PN) bags are available for both initial and maintenance PN in all NICUs and LNUs and consider network-wide standardisation (see also our recommendations about procurement). PN bags should comply with national nutritional recommendations for neonates as well as safety standards, including mechanisms to avoid accidental lipid over-infusion.[135]	Trust pharmacy leads with input from neonatal ODN.	12 months
	e Ensure all neonatal units have access to a pharmacist with competence to provide advice for prescribing and monitoring of PN to complex patients.	Trusts, neonatal pharmacists	12 months

[135] *https://www.england.nhs.uk/publication/patient-safety-alert-infusing-total-parenteral-nutrition-too-rapidly-in-babies/*

Recommendation	Actions	Owners	Timescale from date of publication
12. (continued) Governance and mortality review processes at local and network level must conform to national recommendations and include clear structures for escalation of risk.	**f** Enable staff in all units to regularly practise preparing drugs and infusions commonly used in neonatal intensive care.	Trusts, neonatal ODNs	Immediate and ongoing
	g Prioritise rolling out suitable electronic prescribing systems for neonatal care. These require a high level of involvement from neonatology teams and neonatal pharmacists to ensure the design is fit for purpose. Where the existing trust prescribing system is not deemed safe for neonatal use, it must be suitably adapted, or an alternative product used.	Trusts, neonatal pharmacists	2 years
	h Implement smart pump technology in conjunction with advice and recommendations found in HSIB smart pump report[94] and audit the impact on medication errors in neonates.	Trust and network neonatal pharmacy leads	1 – 2 years
13. Improve prompt recognition, diagnosis and treatment of conditions commonly screened for or assessed in the neonatal period, which are more likely to result in significant clinical harm.	**a** Review the evidence for pulse oximetry screening and work together to support role out of pulse oximetry screening (POS) across all networks.	Neonatal ODNs, LMSs/LMNSs	1 – 2 years
	b Reconsider inclusion of pulse oximetry screening as part of the national screening programme given the increasing number of neonatal units already undertaking universal screening that results in significant regional inequity in identification.	UK NSC	12 months
	c Ensure all hospital and community services have access to transcutaneous bilirubinometry (TcB) in line with NICE guidance.	Trusts, maternity and neonatal service providers	12 months
	d Implement clearly agreed antenatal and postnatal pathways for managing infants at high risk of needing an exchange transfusion in the neonatal period. Delivery should be planned at a site where the neonatal unit has appropriate staffing and expertise on site at all times.	Neonatal ODNs and LMSs/LMNSs, FMNs	6 months
	e Training for staff performing newborn infant checks must include information regarding anorectal anomalies and the fact they may be more likely to be missed when meconium is passed through a fistula.	Trusts, neonatal ODNs, LMSs/LMNSs	Immediate and ongoing
	f Raise awareness of signs consistent with spinal cord anomalies in the newborn period and establish network-wide protocols for initial management and referral pathways. This should be done jointly between paediatric neurosurgical services/networks and neonatal ODNs as part of a wider collaboration between the two networks with regards to neurosurgical pathways (see GIRFT's Paediatric Neurosurgery report).	Neonatal ODNs, paediatric neurosurgical services / networks	6 – 12 months
	g Review NICE guideline: Neonatal Infection (NG195), and HSIB's national learning reports on group B streptococcus (July 2020) and neonatal collapse (Aug 2020) recommendations and amend local guidelines and education material accordingly.	Neonatal and maternity units	6 – 12 months
	h Optimise evidence-based infection reduction strategies and submit accurate verified infection data to NNAP.	Neonatal units, neonatal ODNs	12 months and ongoing

Recommendation	Actions	Owners	Timescale from date of publication
14. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity.	Trusts	Immediate and ongoing
	b Clinicians and trust management to discuss with the legal department or claims handler, the claims submitted to NHS Resolution in the data set, to confirm correct coding to neonatology as claims for neonates can occur in neonatology, paediatrics (including paediatric subspecialties), paediatric intensive care or maternity, all claims for infants <28 days old at the time of the incident, should be reviewed by the respective teams to ensure accurate assignment of the claim to the correct team. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk Note: Coding of claims to neonatology commenced in April 2020.	Trusts	Following completion of above
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trusts panel firm should be able to provide support.	Trusts	Following completion of above
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SI) and where a claim has not already been reviewed as SI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with networks and all front-line clinical staff in a structured format at departmental / directorate meetings (including multidisciplinary team meetings, morbidity and mortality meetings and regional service meetings where appropriate).	Trusts	Following completion of above
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional hubs to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	Trusts	For continual action throughout GIRFT programme

Supporting families

Background

There is increasing understanding of the vital role that parents and families play in supporting their baby whilst in neonatal care. These include improved physiological stability and neurodevelopmental outcomes, increased weight gain and breastfeeding rates, reductions in length of stay and subsequent readmissions to hospital, improved parent satisfaction and reduced parental stress and anxiety.[136, 137] Babies receiving skin-to-skin contact (also called kangaroo care) begin breastfeeding earlier, and there are long-lasting social and behavioural protective effects, even 20 years after the intervention.[138, 139]

Family integrated care models are well described within the literature and extend further the role of the family as primary carer for the baby within the neonatal unit.[140] This is recognised as the best model of care and is reflected in various sets of guidance including the Neonatal Critical Care Review (NCCR) and NICE guidelines.[141]

Achieving this represents a significant practical and cultural change for neonatal care. It requires unimpeded parental access to their baby at all times; specific support and education for all staff and families, including training in the provision of developmentally sensitive care; and investment in facilities to support families whilst they support their baby's care. Funding for investment in network level care coordinators has been made available through the NHS Long Term Plan in FY2020/21, and there is also a commitment to invest in improved parental accommodation—although there is some uncertainty about the availability of this funding post the COVID-19 pandemic.

Facilities for families

Transitional care services

GIRFT key findings:

- 28% of neonatal units identified transitional care (TC) as a high priority for QI.
- A third of units have TC facilities separate from postnatal wards.
- 65% of TC services permit fathers to be resident.
- There is significant variation in TC cot capacity relative to live births and the breadth of services available within TC.

Reducing unnecessary mother-baby separation has been a focus of quality improvement over a number of years through the Avoiding Term Admissions into Neonatal Units (ATAIN) programme.[142] Transitional care services support this, where babies requiring some additional support are managed alongside their mothers, receiving additional support beyond normal newborn care, but without admission to a neonatal unit. Transitional care is included in NHS Resolution's Maternity Clinical Negligence Scheme for Trusts (CNST) (Safety Action 3).[143] The BAPM framework for transitional care (2017)[144] provides detail of what transitional care should offer alongside neonatal services and 28 (18%) neonatal units identified the development of transitional care as a high priority for quality improvement in the GIRFT survey.

[136] *Liu, Ting-Ting & Lei, Meng-Jie & Li, et al. (2018). Effects of parental involvement in infant care in neonatal intensive care units: a meta-analysis. Frontiers of Nursing*

[137] *Head LM. (2014) The effect of kangaroo care on neurodevelopmental outcomes in preterm infants. J Perinat Neonatal Nurse*

[138] *Mekonnen, A.G., Yehualashet, S.S. & Bayleyegn, A.D. (2019) The effects of kangaroo mother care on the time to breastfeeding initiation among preterm and LBW infants: a meta-analysis of published studies. Int Breastfeed*

[139] *Charpak, N (2016), Twenty-year Follow-up of Kangaroo Mother Care Versus Traditional Care. Pediatrics*

[140] *O'Brien K, Robson K, Bracht M, et al (2018) FICare Study Group and FICare Parent Advisory Board. 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.*

[141] *NICE (2019) NG124 Specialist neonatal respiratory care for babies born preterm*

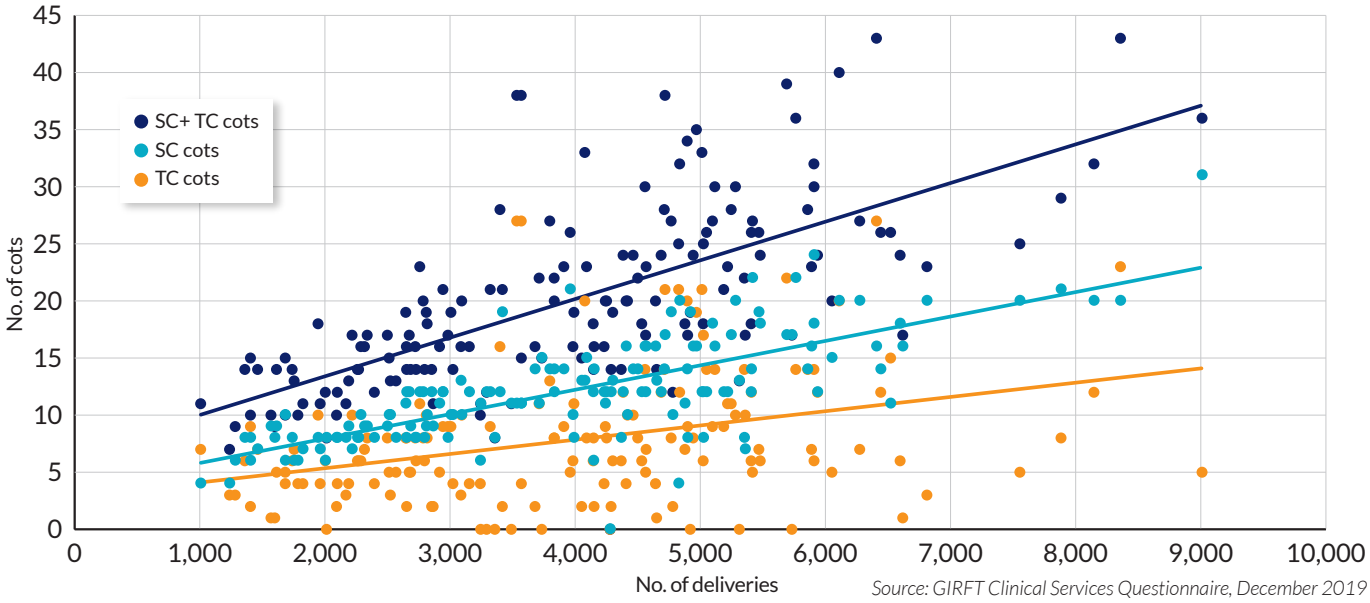
[142] *https://improvement.nhs.uk/documents/764/Reducing_term_admissions_final.pdf*

[143] *https://resolution.nhs.uk/services/claims-management/clinical-schemes/clinical-negligence-scheme-for-trusts/maternity-incentive-scheme/*

[144] *https://www.bapm.org/resources/24-neonatal-transitional-care-a-framework-for-practice-2017*

As expected, there is a positive correlation between the number of transitional care cots and birth rates (**Figure 41**). However, this relationship is not as strong as it is for special care cots and there is very wide variation in the number of transitional care cots available for services of similar size; ten services (6%) had no transitional care service. Only 31% of neonatal units had transitional care facilities which were separate to standard postnatal ward areas and 65% of transitional care units permitted fathers to be resident. Maternity and neonatal services should work together to increase the range of services provided within transitional care to reduce mother-baby separation, and where possible to provide more flexibility for partners to also be caregivers.

Figure 41: Relationship between transitional care (TC) cots, special care (SC) cots and birth rate



Source: GIRFT Clinical Services Questionnaire, December 2019

From deep-dive visits, we observed that transitional care is more developed in some units than others. Some offer care for all babies from 34 weeks, unless they need respiratory support, and sometimes also allow readmission of more preterm infants once they no longer require neonatal high-dependency care. Other units have a more limited scope, particularly if the service does not support tube-feeding. There is much scope for improving transitional care services, even within current footprints, and units must think creatively about how to merge neonatal special care and transitional care services in a flexible way to support best practice and improve quality and experience for families.

Facilities for families receiving neonatal care

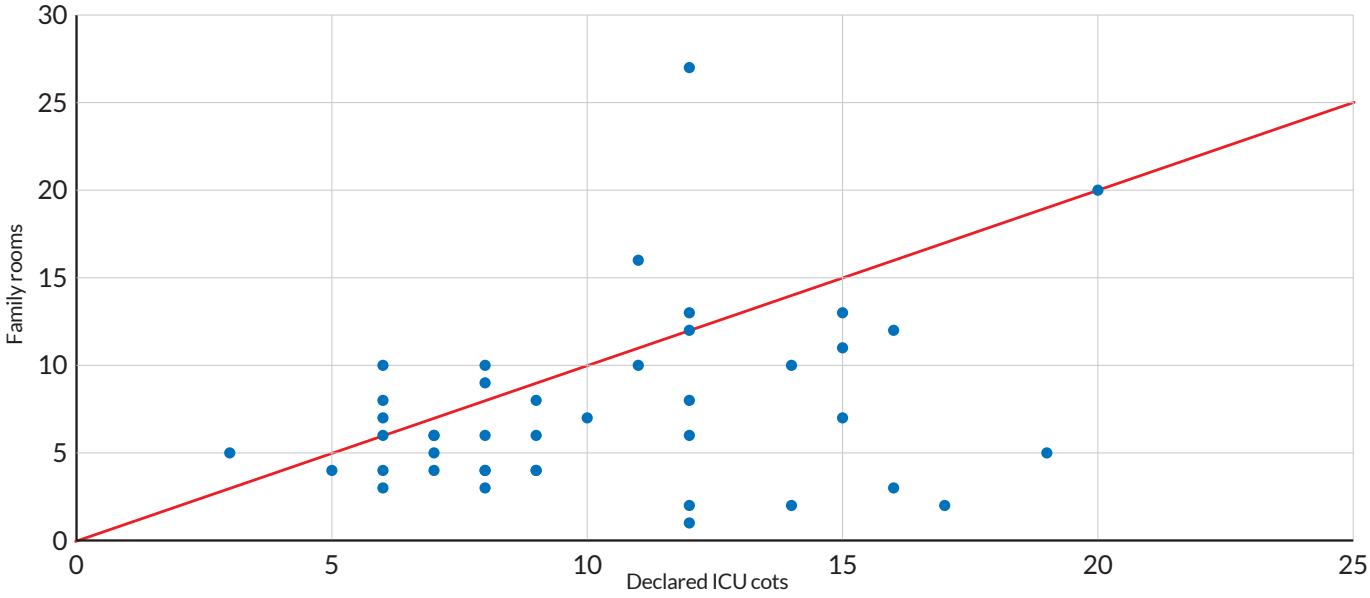
GIRFT key findings:

- 30% of Neonatal Intensive Care Units (NICUs) meet the standard for overnight accommodation for parents of babies in intensive care.
- Only 55% of NICU services have adequate bereavement facilities.
- Half of units had facilities for siblings.
- 73% have kitchen facilities for parents, but only half have dining areas.

There should be dedicated facilities available for parents and families of babies receiving neonatal care as outlined in national documents.[145, 146] There is some evidence to suggest that availability of parent-infant rooms is associated with a lower risk of mortality and major morbidity and a shorter length of stay.[147] Investment in improved parental accommodation is included in the NHS Long Term Plan. Our data shows there remains wide variation across units in the facilities available for families.

Overnight accommodation should be provided for families whose baby is receiving intensive care with one parent room per intensive care cot located within 10-15 minutes' walking distance of the unit.[145] GIRFT data demonstrates that only 30% of neonatal intensive care units currently meet this standard when compared to their declared IC cot base (**Figure 42**). This increases to 60% when compared to average cot occupancy.

Figure 42: Number of family rooms available compared with intensive care cots (black line shows the standard)



Source: GIRFT Clinical and Family Services Questionnaires December 2019

We asked units to rate both the quantity and quality of facilities available for parents (**Table 9**). Their responses show key areas for improvement, including counselling facilities, dining facilities for families and sibling facilities. It is important to recognise the needs of the entire family and providing facilities suitable for young siblings helps reduce stress and improves family involvement in care.

[145] *Department of Health (2009) Toolkit for High Quality Neonatal Services*

[146] *NHS England, Service Specification E08: Neonatal Critical Care https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08/*

[147] *Lehtonen L, Lee SK, Kusuda S, et al (2020) International Network for Evaluating Outcomes of Neonates (iNeo). Family Rooms in Neonatal Intensive Care Units and Neonatal Outcomes: An International Survey and Linked Cohort Study. J Pediatr.*

IN PRACTICE

Supporting siblings to enable family integrated care

Noah's Star

Noah's Star is a volunteer run service which provides engaging activities and supervised play for children, so that their parents can spend time and attend to their premature or sick babies. The project was developed in line with the Family Integrated Care Model which supports parents as partners in care.

All volunteers are appropriately screened and trained (including Enhanced DBS, full employment history explored with two references obtained, two-day compulsory training workshop, monthly reviews and optional webinars).

The volunteers support siblings within a crèche/play environment as well as offering peer support to parents on the unit.

"Noah's Star has made such a difference both for our parents and families and our staff. The Neonatal Unit can be a daunting place for young children and having dedicated volunteers to support siblings is fantastic. It is a key component of our Family Integrated Care project and helps facilitate our parents becoming true partners in their baby's care, safe in the knowledge that their children are in good hands."

Consultant Neonatologist

Table 9: Reported quality of facilities

Proportion of facilities rated as 'sufficient' and 'nearly always sufficient'	Sufficient size or number %	Quality: good or excellent
Privacy screens	77%	75%
Parent sitting room(s)	74%	72%
Family toilet facilities	74%	71%
Breast pumps at bedside	74%	80%
Parent lockers or secure storage	73%	70%
Parent kitchen(s)	73%	63%
Expressing room(s)	69%	64%
Baby changing facilities	68%	50%
Bedside comfortable chairs suitable for prolonged skin to skin care	63%	77%
Counselling room(s)	62%	59%
Breast pumps for hire or loan	57%	62%
Parent dining area/room(s)	52%	46%
Play area for sibling(s)	52%	44%

Source: GIRFT Family Questionnaire, December 2019

To support parent access and family partnership in care, unit facilities should support families to have access to nutritious food 24 hours/day with the minimum of a kitchen area to prepare hot and cold drinks and a microwave to make meals on the unit.[148, 149] Our survey found that 73% units have facilities for parents to make their own hot meals and drinks.

Facilities for families who are bereaved are a cause for concern with only three quarters of neonatal unit's reporting suitable bereavement facilities on site. In NICUs, where most neonatal deaths occur, only 55% had good facilities and 9% had no facilities (**Figure 43**). The National Bereavement Care Pathway includes a range of resources to guide professionals on how to improve the quality and consistency of bereavement care received by parents in NHS trusts after pregnancy or baby loss.[150]

[148] *Department of Health (2009) Toolkit for High Quality Neonatal Services*

[149] *www.bliss.org.uk/health-professionals/bliss-baby-charter/what-is-the-bliss-baby-charter*

[150] *https://nbcpathway.org.uk/about-nbcp*

Figure 43: Bereavement facilities in neonatal intensive care units

Source: GIRFT Clinical Services Questionnaire, December 2019

All trusts/networks should understand the gap in provision of facilities for families, in line with national recommendations and develop business cases and action plans to address any shortcomings. Whilst many current neonatal unit footprints constrain the ability to increase the size of parent facilities, every effort should be made to ensure facilities provided are fit for purpose. It is vital when any new build or refurbishment of neonatal units is undertaken that parent facilities are given a high priority and that there is parental input into design, using national and international guidance to support the right approach to neonatal unit design.[151]

Financial burden on families

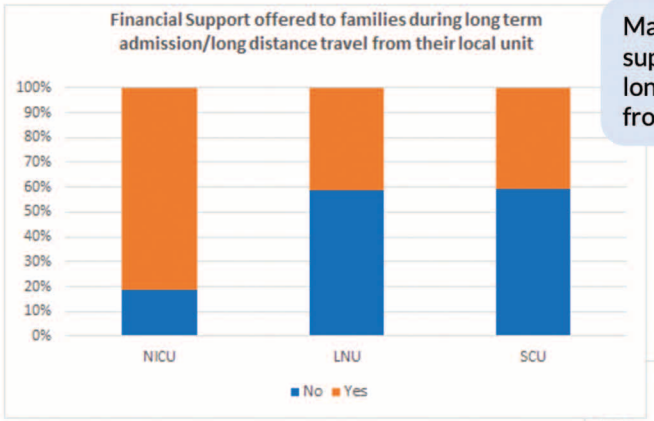
There is a significant financial burden on families whilst their baby is in neonatal care.[152] Families can be travelling and/or staying away from home for many weeks and support with travel and subsistence costs are included in the national service specification and Department of Health (DoH) Toolkit, whilst Bliss, the baby charity, strongly advocates free parking. It is clear from the GIRFT data that financial support provided is highly variable across car park charges, travel, food and drink subsistence. This is summarised in **Figure 44**. Our data shows that in many cases, financial support to parents is partially or totally reliant on local charitable funding.

[151] *See for example, the Department of Health's Health Building notes for neonatal units https://www.gov.uk/government/publications/guidance-on-the-planning-and-design-of-neonatal-units*

[152] *Bliss (2021) Families kept apart: barriers to parents' involvement in their baby's hospital care https://www.bliss.org.uk/research-campaigns/our-campaigns/families-kept-apart-take-action-now/families-kept-apart-report*

Figure 44: Financial burden on families of the neonatal journey

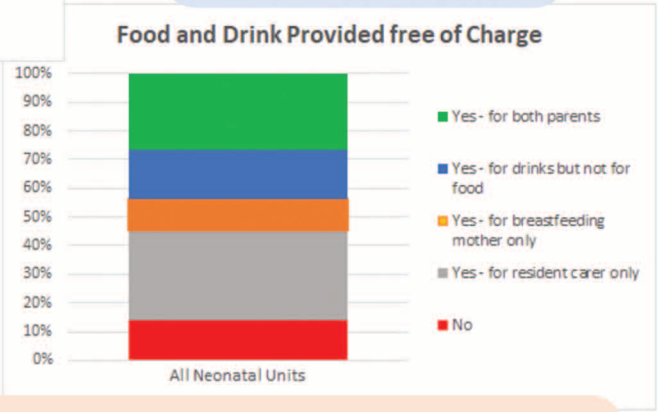
Bliss research estimates that having a baby in neonatal care costs on average an additional £2,256 per family



Many units do not offer financial support to families during long-term admissions away from their local units

Financial burden of car parking with **40% of units still charging neonatal families for car parking** with an average cost of £7 per day

What parents say:
"We could only visit our baby two days a week when she was being cared for in the NICU. This carried on for six weeks. We were simply unable to afford to travel there every day."
Mum of a baby born at 27 weeks



What parents say:
"I had to use my credit card to pay for the extra food costs while our baby was in hospital. We hadn't budgeted for this extra expense while I was on maternity, and had no other way to pay."
Mum of a baby born at 33 weeks

What parents say:
"Family and friends had given us money to spend on the babies as a gift for their birth, but I had no choice but to spend it on food and travel costs instead"
Mum of twins born at 32 weeks

Average number of parents per day with a one-way travel time more than 1 hour - NICUs

Neonatal ODN	Median
London - South	5.04
TV & Wessex	3.75
South West	2.80
E Midlands	2.18
E of England	2.06
Yorkshire & Humber	1.89
London – NW	1.77
Northern	1.36
North West	1.28
London – NC&E	0.84
South East	0.73
West Midlands	0.57
Total	1.52

On average each day, every NICU has one to two sets of parents that must travel more than an hour each way to be with their baby

Source: GIRFT Families Questionnaire December 2019 and Bliss

Neonatal care presents a very significant financial burden to families. The current financial provision for families is inequitable. Network care coordinators should work with trusts to understand the current arrangements and gap in provision and aim to provide a more consistent level of support across the network. Sharing of this data across networks will allow an understanding of the variation nationally and support the potential future development of national guidance on this issue.

Family partnership in care

GIRFT key findings:

- 46% of units offer short-term home tube-feeding support.
- 31% of units allow parents to present their baby on ward rounds.
- 84% of units are actively participating with Bliss Baby Charter audit tool, and 5% are fully accredited.
- 29% of units are participating in UNICEF Neonatal BFI with eight neonatal units fully accredited with many units and networks seeking financial support to participate.
- The effect of the COVID-19 pandemic on parents' ability to be their baby's primary carer has been profound.

There is clear evidence that family partnership in the care of neonates is beneficial for long-term outcomes of babies and their families. Support for trusts in implementing this cultural change in practice is currently available through use of the Bliss Baby Charter audit tool[153] and UNICEF Neonatal Baby Friendly Initiative (BFI).[154] There are also more specific neurodevelopmental educational resources available, such as the Early Babies Family[155] and Infant Neurodevelopmental Education (FINE)[156] and the Newborn Individualised Developmental Care and Assessment Programme (NIDCAP).[157] An eagerly anticipated BAPM Framework for practice regarding Family Integrated Care published in November 2021 provides additional resources to support the implementation of this improvement to neonatal care.*

Family partnership in care empowers parents to have as much contact with their baby from birth (including offering birthday cuddles in the delivery suite) and throughout the neonatal unit stay with the support and training of the neonatal team. GIRFT asked a series of questions around family involvement in care with many units showing good standards in family-centred care areas such as 24-hour access and the opportunity to provide skin to skin contact. Key areas requiring additional focus are shown in **Table 10** which gives a pre-COVID-19 pandemic snapshot on the levels of family involvement in the areas requiring the most improvement. Visits at both network and trust level have emphasised the need for staff with specific training and focus to lead on this area, and the role of allied health professional (AHP) staff is integral within such initiatives.

[153] *www.bliss.org.uk/health-professionals/bliss-baby-charter/what-is-the-bliss-baby-charter*

[154] *www.UNICEF.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/neonatal-guide-to-the-standards/*

[155] *https://www.earlybabies.com/news-events/*

[156] *www.bliss.org.uk/health-professionals/training-and-events/fine*

[157] *www.nidcap.org/*

** Family Integrated Care: A Framework for Practice (BAPM, November 2021) https://www.bapm.org/resources/ficare-framework-for-practice*

Table 10: Family involvement in neonatal care – summary of responses to GIRFT's questionnaire

Family involvement	% of units answering "always" or "mostly"			
	NICU	LNU	SCU	England mean
If they want to, are parents allowed to present their baby on a ward round?	35%	33%	22%	31%
If they want to, are parents allowed to take and record observations e.g., temperature, once they have achieved competency?	53%	40%	27%	41%
If they want to, are parents allowed to give oral medications once they have achieved competency?	65%	65%	57%	63%
Is there a programme to support home tube feeding for well preterm infants in your unit?	70%	40%	30%	46%

Source: GIRFT Family Questionnaire, December 2019

IN PRACTICE

Introducing the Family Integrated Care model

Leeds Teaching Hospitals NHS Trust

Leeds Teaching Hospitals NHS Trust introduced a Family Integrated model of Care (FICare) in 2015, and across the entire split site service in 2017.

The trust developed a staff education package that explained the concepts of FICare, why it works, how it works and what to do to make it work. This included understanding adult education, improving communication skills and learning teaching skills. The team developed a well-structured education programme for parents – a three-week rolling programme with documentation to support it.

On a very limited budget, the unit was able to improve its parent environment, including improving a small kitchen for families and providing comfortable bedside chairs to enable parents and families to spend as much time as possible with their newborns. The team gathered a wealth of information to share with families to support them with clinical care, transport, accommodation and finances.

An important learning was that plans had to flex and adapt, depending on what the current group of parents needed, what staff were available and what resources could be found. Parents are listened to, and they complete surveys during and after their stay. As an example, feedback showed that the planned parent teaching programme didn't suit many families – they wanted evening and weekend teaching when partners could attend.

Over the years the team have added many elements to the trust's FICare package. Pre-COVID-19, there were several sessions in the week where parents could get together to do activities and share stories. These included arts and crafts in a "Memories and Milestones" session, Beads of Courage, coffee mornings and dad's pizza nights. The team has gained a psychology counsellor to support families and had support from psychology, sibling support and many social events. There are parent social media groups and the use of vCreate (the secure video sharing platform). Activities are supported by a group of amazing volunteer parents that support all FICare activities and have been invaluable.

An important lesson is that the success of FICare does not depend only on planning and resources. It is the culture change of healthcare professionals moving away from the traditional model of neonatal care and embracing parents as partners in care – respecting the essential role they have in their infant's wellbeing and recovery. Each member of the team must be invested in it, from managers and matrons to doctors and support services. Whilst nursing colleagues deliver the bulk of FICare, everyone's attitude and ethos impacts on success.

The COVID-19 pandemic has clearly made delivering FICare challenging. Parental access and family visiting policies were drastically affected in the first lockdown and many units still cannot allow extended family or siblings to visit. Delivering education and supporting activities have had to be re-thought and shared in a different way – social media and video/FaceTime platforms have been well used.

Excellent care, FICare, can be delivered on passion and belief in supporting parents to be parents from the very beginning. It does not rely on financial resource but a firm belief in the importance of parents in their baby's neonatal journey, to improve long term outcomes for babies and families.

Parent education

A standardised education package for parents, the 'parent passport' has been developed by several neonatal ODNs to ensure parents' competencies are taught and signed off in the same way across all network hospitals. This provides consistency for parents to continue care for their baby when they move between sites and provides confidence to staff working at different sites that parents have received the same training competency level. It is strongly recommended that all networks should adopt this approach.

IN PRACTICE

Impact of the parent passport

Yorkshire and Humber neonatal ODN

Areas of improvement in the flow of the Yorkshire and Humber network brought about several pieces of work, one of which included a collaborative network approach with parental representation to developing a parent passport. Parents can feel disconnected from their baby on a neonatal unit but this can be overcome by reducing barriers and empowering parents to be partners in care. Parental feedback found that repatriation back to home units may cause some anxiety due to inconsistent parental involvement and different ways of undertaking care practices.

The development and foundation of the parent passport involved the Family Centred/integrated care (FINE) model and enabled units to share good care practice and develop packages locally but with the frameworks and core elements being agreed network wide. All elements underpinning the parent passport included neurodevelopmental care. Examples of parent competencies include drug administration, tube feeding, mouth care, kangaroo care, bedside charting e.g., temperature and weight and participation in ward rounds.

Staff were encouraged to undertake further training and dissemination of FINE care and utilise the practices when involving/teaching parents in the care of their baby. A network transfer sheet was designed listing each core component of care that parents have completed with a section to add comment for parents requiring further support. This accompanies their baby on transfer together with any relevant unit care package as required. The parent passport continues to be developed and updated and will form part of the care coordinator work.

Bliss Baby Charter audit tool

The Bliss Baby Charter is a long-standing practical framework and standard for assessing and driving quality improvement in family-centred care. GIRFT data suggested 139 (89%) units were utilising the Bliss Baby Charter audit tool, although on deep-dive visits it was apparent that this was not a focus for some neonatal units, particularly where there was no multidisciplinary involvement. There has also been a pause in this QI work for many units during the pandemic, with many restarting work from April 2021. Further data provided by Bliss in January 2021 is shown in **Table 11**.

Table 11: Progress to accreditation of Bliss Baby Charter standards

Bliss Baby Charter stage	Proportion of Units
Registered but have not submitted an audit	16%
Working on 2nd audit	36%
Working on 3rd audit	32%
Ready for accreditation assessment	4%
Bliss accredited/awaiting reaccreditation	5%
Not registered	7%

Source: Bliss, 2021

The Bliss Baby Charter accreditation will require funding from April 2021, although the audit tool will remain free of charge and its continued use as an audit tool is recommended. Neonatal services will need to find financial support to undertake full accreditation as there is no nationally agreed funding source identified and this may impact on future Bliss accreditation levels.

UNICEF Neonatal Baby Friendly Initiative

UNICEF has developed an evidence-based programme for use in Neonatal units, the UNICEF Neonatal Baby Friendly Initiative (BFI), with staged accreditation to improve support for breast milk production and breastfeeding as well as supporting close parent-infant relationships and parent partnership in care.[158] From data provided by UNICEF, in April 2021, currently 29% of units are engaged with the UNICEF Neonatal BFI programme and there are eight accredited neonatal units across England. Further work is underway with a network approach being taken in a further 34 units.

Data from GIRFT and NNAP demonstrate wide variation in breast milk administration for preterm babies at all stages during their stay in hospital (see the discussion under clinical aspects of care, from page 63-65 onwards). The benefits of breast milk in this population are even greater than in their term counterparts, although we note the need to support mothers sensitively so they do not feel under pressure to breastfeed/express breast milk.

The NHS Long Term Plan has already committed funding to all maternity services not already accredited to undertake an evidence-based infant feeding programme, such as the UNICEF Maternity BFI, because of the wide variation in breastfeeding rates in term infants nationally. Currently, there is no nationally agreed funding mechanism for achievement of the UNICEF Neonatal BFI accreditation across all units. Some networks have achieved funding for this through local maternity and neonatal systems or from neonatal ODNs, whilst others are unable to access funding.

It is strongly recommended that central funding is considered for neonatal UNICEF Neonatal BFI, to match the commitment given to feeding support for the well term infant as well as providing structured support for improving family involvement in neonatal care.

[158] *https://www.UNICEF.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/neonatal-guide-to-the-standards/*

Parental involvement and COVID-19

Thankfully, most babies are not clinically affected by COVID-19. However, the overall effect on parents and families has been profound. Parents and family should never be viewed as visitors to a neonatal unit and must be recognised as key caregivers. Unfortunately, many units report that parent access has been significantly reduced during the COVID-19 pandemic due to physical space within nurseries or the inclusion of neonatal services within wider trust visiting policies. During GIRFT unit visits, we observed variation in the extent to which neonatal units were able to persuade their trusts to treat parents as caregivers and support good access. All units visited felt that family involvement in care had been significantly impacted by the pandemic. This is confirmed in research by Bliss into the impact restrictions imposed on neonatal units.[159] Both Bliss and BAPM have developed a position statement to help parents and advise trusts on local policies to support parental access during the pandemic as well as producing letters for use by neonatal units to their trust board of executives to support better parent access.[160, 161]

COVID-19 has also changed the way that newborn babies are cared for within the neonatal setting. Facemasks risk impacting relational development and general measures around social distancing and reduced interactions may disrupt the normal development of bonding and connections with others. A study discussing the potential impact of facemasks in the newborn period recommends that health professionals should understand the effects of prolonged mask wearing to minimise any potential long-term impact on neonatal development and optimise psychological outcomes for babies, infants, children and their parents. It is strongly recommended that the use of clear face masks, where available, should be prioritised in neonatal settings to reduce the potential neurodevelopmental impact in this vulnerable group of babies.[162.163]

Staying connected during the pandemic

vCreate[164] is a secure video messaging service that helps patients, families and their clinical team stay connected. In response to the reduction in parent and wider family access to neonatal units during the pandemic, national specialised commissioning prioritised funding to support the implementation of vCreate for every neonatal unit in the country for 12 months to support families during the pandemic. The impact of this offer has been widely recognised with the impact on individual families clear to see (**Figure 45**). Whilst vCreate use increased due to this support of funding through the pandemic nationally, BadgerNet Baby Diary offers an alternative to this and units across the country have embraced digital communication with families utilising iPads for FaceTime and telemedicine to keep families connected to their babies. These additional technologies should continue to be utilised beyond the pandemic restrictions to maintain additional contact methods for families, although we suggest additional research is needed to evidence the benefits. These technologies should not be used as a substitute for free parent access.

[159] *Bliss (2021) Locked out: the impact of COVID-19 on neonatal care https://www.bliss.org.uk/news/2021/bliss-research-shows-devastating-impact-on-bonding-with-their-baby-when-parents-are-locked-out-of-neonatal-care-due-to-covid-19-restrictions*

[160] *https://www.bliss.org.uk/health-professionals/information-and-resources/parental-access-covid19*

[161] *https://www.bapm.org/posts/269-bapm-write-letter-to-trusts-in-support-of-unrestricted-parental-access*

[162] *Janet Green, Lynette Staff, Patricia Bromley, Linda Jones, Julia Petty, (2021) The implications of face masks for babies and families during the COVID-19 pandemic: A discussion paper, Journal of Neonatal Nursing*

[163] *C. Harding, A. Aloysius, N. Bell, et al (2021) Reflections on COVID-19 and the potential impact on preterm infant feeding and speech, language and communication development, Journal of Neonatal Nursing*

[164] *www.vcreate.tv/*

Figure 45: Examples of anonymised parent-baby messages during wave 1 of the COVID-19 pandemic

Source: v-Create, 2020

Family partnerships in care - summary and conclusions

Neonatal units need to recognise the importance of family-centred care in improving outcomes for babies and supporting development of close and loving relationships within families. Progress across units is variable, and involvement and leadership from across the multidisciplinary team, including Allied Health Professional workforce, is vital to achieve a long-term change in culture.

The pandemic has had a major impact on family involvement in care; neonatal units and national bodies must continue to champion the needs of the preterm infant and their family to ensure their status as carers (not visitors) is understood and potential neurodevelopmental consequences of necessary COVID-19 interventions, such as facemasks, are minimised.

Nationally agreed quality improvement tools are important to support units in implementing best practice. GIRFT is recommending units work towards accreditation for neonatal UNICEF Neonatal BFI, if a sustainable funding source can be found and strongly supports central funding for this project in line with that provided for well term infants. GIRFT recommends the use of supporting tools such as Bliss Baby Charter and the recently published BAPM Family Integrated Care Framework to support quality improvement locally and as a focus to build towards a family partnership model.

The NHS Long Term Plan has committed to funding for network care coordinators within each ODN in England. The focus of this role is to ensure the offer of family partnership is supported across a network footprint. This should include supporting development of parent passports to provide consistency for parents to continue care for their baby when they move between sites. A unified approach across networks will further improve family experience and reduce the stress associated with moving between services.

Family wellbeing

GIRFT key findings:

- Admission to neonatal units is associated with significantly higher rates of perinatal mental health difficulties compared to normal birthing population.
- Only half of NICUs and very few LNUs and SCUs reported having a regular psychology service.
- Access to community perinatal mental health services is difficult due to parents being resident in neonatal units for several weeks, often a long way from home.

Admission to a neonatal unit for any reason can have negative psychological consequences for parents, babies and the parent-baby relationship[165,166] with significantly higher rates of parental mental health difficulties when compared to the general perinatal population.[167, 168] Moreover, the environment itself can be traumatising.[169] Effective and timely psychological intervention results in a number of cost benefits including shorter length of stay and improved outcomes for parents and infants which are sustained over time.[170] Awareness raising and the opportunity to understand the neonatal environment ahead of experiencing neonatal care is important for families and work should be done to improve antenatal education including opportunities for virtual tours of the neonatal services to improve access to information for all families when they need it.

The support of family wellbeing throughout the neonatal journey is vital to ensure a good family outcome following discharge. Parents spend significant periods of time on neonatal units, often for many weeks. In many instances, where the baby is not in the local hospital, parents and families may be resident in accommodation a long way from home. For these reasons, it is more difficult to access the existing perinatal mental health services which are local and community based. On-site neonatal support is therefore required, including peer support, access to psychological support and a neonatal workforce who are psychologically aware of the impact on families. These services should link seamlessly with community perinatal mental health services following discharge to allow a space for families to seek support, during and in the year after their neonatal journey, at the most appropriate time for them.

IN PRACTICE

Neonatal Families and Staff Together (NFaST)

ODN and Spoons Charity

A project is underway by the North West ODN and Spoons to scope the needs of neonatal families around psychological and peer support provision during and after the neonatal journey. The project aims to model what a good, locally-driven provision could look like and evaluate the impact of interventions to support families and staff. Training sessions utilised within the project include neonatal staff, parents and the wider MDT. A composite of resources will be available to support the implementation of peer support in neonatal units. An evaluation of this project is available at https://www.neonatalnetwork.co.uk/nwnodn/cheshire-and-merseyside/family-peer-support/.

[165] *Grunberg VA, Geller PA, Bonacquisti A, Patterson CA. (2018) NICU infant health severity and family outcomes: a systematic review of assessments and findings in psychosocial research. J Perinatol.*

[166] *See, for example, Bry A, Wigert H. (2019) Psychosocial support for parents of extremely preterm infants in neonatal intensive care: a qualitative interview study. BMC Psychol.*

[167] *Nancy Feeley, Phyllis Zelkowitz, Carole Cormier, et al (2011) Posttraumatic stress among mothers of very low birthweight infants at 6 months after discharge from the neonatal intensive care unit, Applied Nursing Research*

[168] *Lefkowitz DS, Baxt C, Evans JR. (2010) Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the Neonatal Intensive Care Unit (NICU). J Clin Psychol Med Settings.*

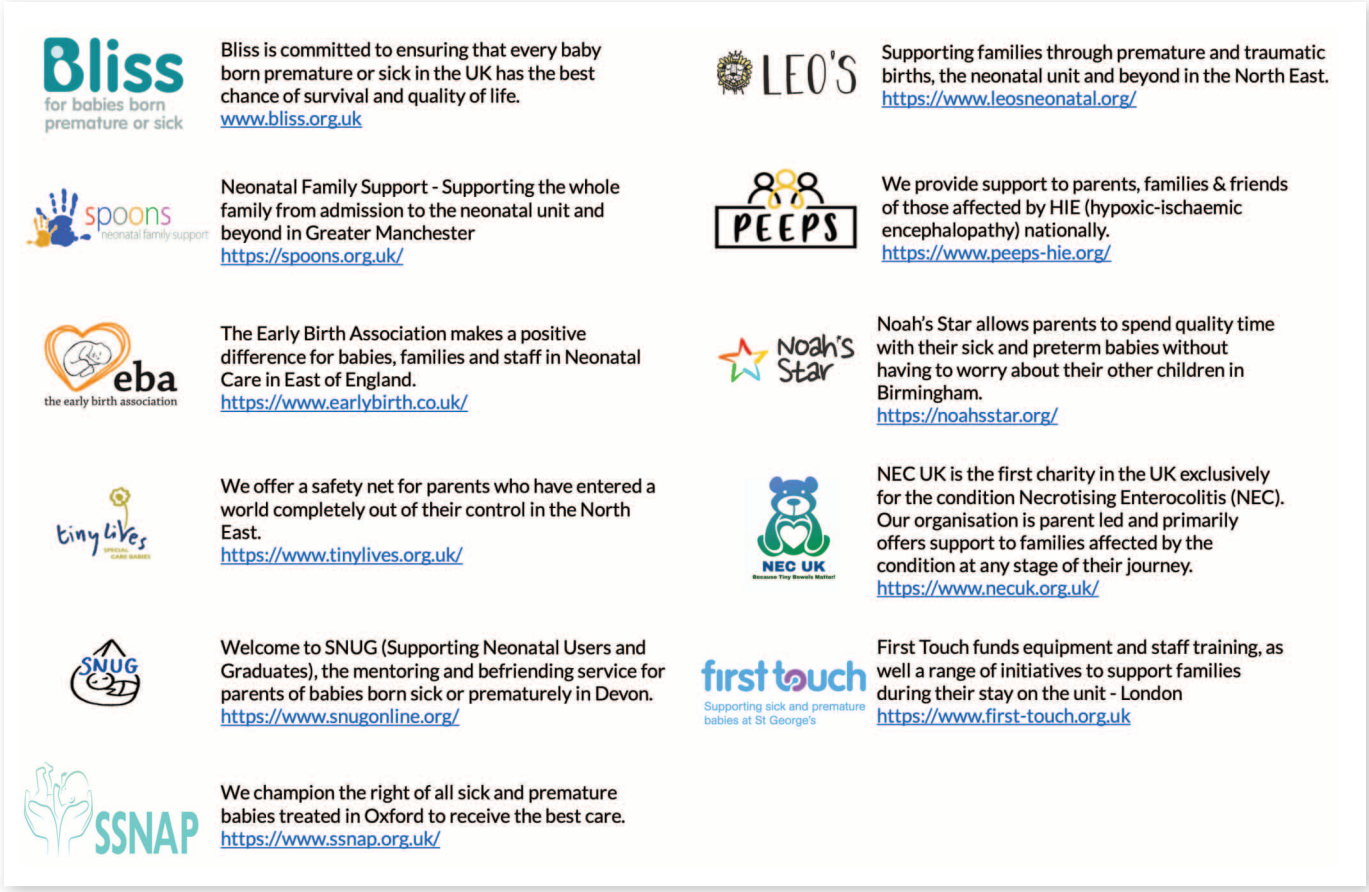
[169] *Obeidat HM, Bond EA, Callister LC. (2019) The parental experience of having an infant in the newborn intensive care unit. J Perinat Educ.*

[170] *Cherry AS, Mignogna MR, Roddenberry Vaz A, et al. (2016) The contribution of maternal psychological functioning to infant length of stay in the Neonatal Intensive Care Unit. Int J Womens Health.*

NICE has issued guidance on the provision of antenatal and postnatal mental health care.[171] Despite this, GIRFT data demonstrates a very significant shortfall in psychology service provision (see GIRFT key findings and further information in the GIRFT Neonatology Workforce Report). This picture is very disappointing, particularly given the significant focus and funding for perinatal mental health (PMH) which was part of the NHS Mental Health Implementation Plan 2010-24 (a £2.3 billion investment). PMH funding has been channelled into increasing the availability of specialist community care for women who need ongoing support from birth to two years. Unfortunately, this will not meet the needs of some of the high-risk families whose baby is resident on the neonatal unit for the reasons outlined above. **There has not been any specific funding allocation for increased psychological support for PMH needs within neonatal units.** Funding allocated for neonatal AHP support in the NHS Long Term Plan will provide a small amount of network-level provision but will not impact the very significant gap in local service provision.

Local charities and peer support offers are a vital link for neonatal units. Historically local charity support often lent itself to fundraising for equipment, but there is now much more on offer to support families whilst on the neonatal unit and during the transition from neonatal unit to home. Peer support is a vital part of this offer and the value of peer support from those with lived experience of the neonatal unit offers an additional layer of support to families that staff are unable to provide. Peer support both within the neonatal unit and following discharge home should be seen as an essential part of the local family support offer and will often be offered by third sector organisations. The use of remote support using digital technologies and social media offer opportunities for support even during times where community support is reduced (**Figure 46**).

Figure 46: Examples of local and national charities offering support to families in neonatal care



Source: GIRFT

[171] *NICE (2020) CG192 Antenatal and postnatal mental health: clinical management and service guidance; NICE (2016) QS115 Antenatal and postnatal mental health*

Family wellbeing - summary and conclusions

There is a paucity of psychological support available to families who are at higher risk of PMH difficulties relative to the general perinatal population. PMH services should be accessible to neonatal families from within the neonatal services with seamless links to community perinatal mental health services as and when they are appropriate for an individual family. Given the size of the current gap, this will not be possible without access to specific funding.

We are recommending that neonatal units link to parent voices to support a clear understanding of what local parents need and to work with local charities and local mental health services to improve support and provide appropriate signposting.

Network-funded psychology posts (see practice example in GIRFT Neonatology Workforce Report) should develop and deliver appropriate training for all staff groups, particularly those working in the community, who have little direct experience of neonatal care, to raise awareness about the psychological impact of the neonatal journey on families.

Parent voice

To support improvements across neonatal services, the parent voice must be heard at both unit and network level. This parent voice should have lived experience of the neonatal journey and must be local and inclusive to ensure the voice of a wide demographic of parents can be accessed and heard and local considerations/challenges are integrated within all network level planning.

Network input

GIRFT key findings:

In October to December 2019:

- Only 60% of networks had parental representation on the network board.
- 50% of neonatal networks had parent advisory groups.
- 40% of neonatal networks had good levels of parental engagement in network activities.
- 90% of units had sought parent feedback in the last 18 months.

At network level we found a general lack of parental presence in network functioning in at least half of ODNs. At deep-dive visits it was clear that some networks were making progress to set up parent advisory groups but financial impediments to support this remain in some networks. Some networks are working with local Maternity Voices Partnerships (MVPs) to develop Maternity & Neonatal Voices Partnerships (MNVPs) or Neonatal Voices Partnerships (NVPs). Where a Clinical Commissioning Group (CCG) or Local Maternity System (LMS) have extended some Chair funding to cover neonatal time, MVPs have much evidence to argue that for a parental voice to fully integrate in transformation and sustainable services, these voices need to be remunerated. There needs to be a continued focus on parental involvement to ensure this is embedded into all aspects of network activity.

IN PRACTICE

Parent Advisory Groups across a network

North West neonatal ODN

Parent Advisory Groups (PAGs) form a vital part of an ODN's ability to provide genuine family partnership in care. A PAG enables parents to become partners in service design and delivery and to collaborate with providers in a meaningful and effective way, through both the lived experience of the PAG members themselves and their subsequent in reach into the broader neonatal community.

In North West England, there are three locality PAGs, which also work together to provide network-wide support when appropriate. This model has been effective in driving forward standards around FICare, perinatal mental health and parent infant mental health support for parents, as well as informing the development of clinical practice considering the parent experience.

Local parent feedback

Seeking feedback from local parents and using this feedback to support improvement is vital within a service and important for families to see they are being listened to and their feedback matters. Many units have '*You said, we did*' boards which is a simple way of sharing actions from parent feedback.

Evidence from the GIRFT family questionnaire demonstrated 90% of all units have sought parent feedback and used this to support local actions. Some of the actions from this feedback are summarised in **Figure 47**.

Figure 47: Unit actions following local family feedback

Source: GIRFT Family Questionnaire December 2019

All units are encouraged to have a formal process to hear family feedback and to display changes made in response to this feedback. Widening the net of receiving feedback beyond the neonatal unit at discharge will support more realistic feedback and further improve services. Management of this post-discharge parent feedback could be at network level to allow opportunities for open and honest feedback.

Recommendations for improving the support given to families

Recommendation	Actions	Owners	Timescale from date of publication
15. Facilities for families should allow parents to remain with their baby at all times if their circumstances permit.	**a** Increase the range of services provided within transitional care to reduce mother-baby separation, and where possible to provide more flexibility for partners to also be caregivers.	Trusts, neonatal ODNs, maternity services, network care coordinators	2 – 5 years
	b Urgently address inadequate or poor-quality counselling and bereavement facilities. Seek input from families to determine needs.	Trusts	6 – 12 months
	c Work with families to understand the gap in provision of facilities and address inequities, in line with established guidance.[172] Where new units are planned, parent facilities should receive the same priority as clinical space.	Trusts, neonatal ODNs, network care coordinators	2 – 3 years
	d Research and determine what tailored support can be made available for siblings.	Trusts	2 – 3 years
16. There must be consistent and equitable financial support for parent travel, subsistence and accommodation requirements.	**a** Benchmark current financial support available to families including parking, accommodation, food and drink and travel costs, making best use of available evidence.	Neonatal ODNs and trusts, with input from Bliss	2 years
	b Share network findings with the Neonatal CRG and BAPM to support alignment nationally.	Neonatal ODNs, neonatal CRG, BAPM, with input from Bliss	2 years
	c Provide consistent and equitable financial support to families across the network. Ensure families are aware of their statutory entitlements and how to claim.	Trusts, neonatal ODNs, local charities	2 – 5 years
	d Provide free, or discounted, parking for all parents of neonatal inpatients for the duration of their stay.	Trusts,	2 – 3 years
17. Family Integrated Care must be fully embedded in all neonatal services and networks should ensure family training and involvement in care are the same across different providers in the baby's journey.	**a** Consider a unified approach across the network to improve the journey for families transferred between providers. This should include development of parent passports to provide consistency for parents to continue care for their baby when they move between sites.	Regional neonatal ODNs, network care coordinators	2 – 18 months
	b Parents must be considered as essential carers not visitors. Nationally, continue to champion the needs of families in neonatal units during world events that potentially restrict patient access (e.g. the COVID-19 pandemic) in order to reduce the potential neurodevelopmental consequences of these restrictions.	Neonatal CRG, Bliss, NNA and BAPM	Immediate and ongoing
	c Ensure every provider of neonatal care has a clear action plan for ongoing development of partnership care with families using QI tools such as the Bliss Baby Charter, UNICEF Neonatal BFI (see action 8b) and BAPM Framework for Family Integrated care. This work should have senior nursing and AHP leadership involvement alongside the family voice.	Trusts, neonatal ODNs, network care coordinators and network AHPs	6 – 12 months

[172] *https://www.gov.uk/government/publications/guidance-on-the-planning-and-design-of-neonatal-units*

Recommendation	Actions	Owners	Timescale from date of publication
18. Psychological support services should be accessible to all families during their stay in the neonatal unit, with seamless links to community perinatal mental health services as and when they are appropriate for an individual family.	**a** Benchmark the level of psychological support required against the current standard (BPS Perinatal Services 2016) and the anticipated neonatal standards due to be set by the British Psychological Society (see workforce report recommendation 2b).	Trusts, supported by network psychology leads	1 – 2 years
	b Actively address the psychological needs for the whole family throughout the neonatal unit journey and post discharge. There is a major gap in access and provision of Perinatal Mental Health support for these families and this must be addressed. This needs to be taken forward both locally and nationally.	NIB, national & regional specialised commissioning teams, PNMH/neonatal ODNs, trusts	2 years
	c Encourage local and regional links to peer support groups and charities to support improved psychological support.	Neonatal ODNs, network psychology leads, trusts, local charities	6 – 12 months
	d Raise awareness of the psychological impact of the neonatal experience on families among all professionals but particularly those working in the community who have little exposure to neonatal care.	Neonatal ODNs, network psychology leads, network care coordinators, network AHPs	12 – 24 months
19. Robust mechanisms must be in place to include a wide range of parent voices with diverse backgrounds and neonatal experiences in service development and quality improvement across networks and trusts.	**a** Make available Neonatal Parent Advisory Groups/ Neonatal Voices Partnerships or equivalent across all neonatal networks. Links made to MVPs and other parent voice provisions within the local area provide a wide-reaching voice to a diverse population.	Neonatal ODNs, LMSs/LMNSs, MVPs and trusts, care coordinators	6 – 12 months
	b Ensure each local provider of neonatal care has a robust mechanism for parent feedback. This may be developed at a network level.	Neonatal ODNs, network psychology leads and/or care coordinators, trusts	6 – 12 months
	c Ensure there is a mechanism for parents to show how their feedback has been actioned and how this has affected change. This should be updated at least biannually.	Trusts, care coordinators	6 – 12 months

Data capture and reporting

Current data flows

GIRFT key findings:

- BadgerNet is an integral part of neonatal data collection for clinical information sharing across trusts and networks, collection of NCCMDS data for payment and national cost collection and collection of national audit (NNAP) and research (NDAU) data
- Accurate dataflows to SUS and National Cost Collection are not universal.
- There are particular issues with submitting NCC data against the correct facility and use of NCC recommended relative weightings for the specialist Neonatal Critical Care HRGs
- Benchmark prices for Neonatal Critical Care HRGs were finalised and published in the Section 118 Consultation as part of the national payment system 2021/22 in May 2021

Neonatology is fortunate that for many years, all neonatal units in the UK have collected data on a single system (BadgerNet). This is a specific neonatal system that has been adapted and developed with extensive involvement of staff working within neonatology. Data collected from the system is used for a variety of purposes summarised in (**Figure 48**). Specifically:

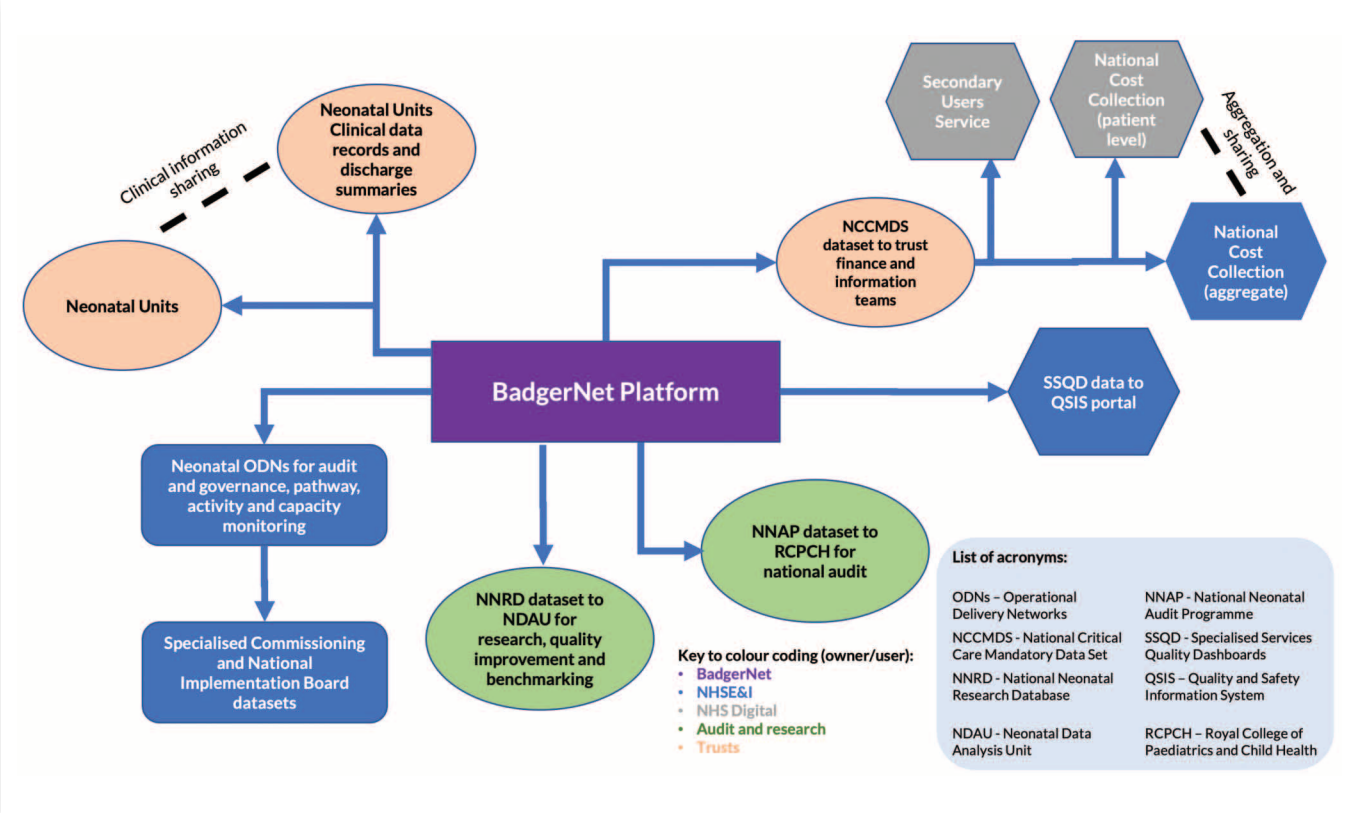
- BadgerNet is used by clinical staff for collated clinical information containing diagnoses, procedures and ongoing care requirements.
- All clinical data on the patient is visible across the neonatal units where the patient has been cared for and may also include the transport record, where the neonatal transport service uses the system (which is the case for the majority of neonatal transport services).
- Neonatal operational delivery networks (ODNs) use BadgerNet data from across their network for audit and governance purposes and to monitor pathways, activity and capacity across the network in near real time. Key summarised data is passed on to regional specialised commissioning teams and the Neonatal Implementation Board.
- Collection of the daily data items are required for the Neonatal Critical Care Minimum Data Set (NCCMDS[173]), which are used to generate the specialist neonatal Healthcare Resource Groups (HRGs) occurring in neonatal units, transitional care or maternity wards. This information can be used by trusts to submit data to Secondary Uses Service (SUS) for payment and commissioning use and can also be used to inform trust submissions to the National Cost Collection (formerly known as Reference Costs).
- BadgerNet enables collection of data for the National Neonatal Audit Programme (NNAP) run by Healthcare Quality Improvement Partnership (HQIP), which is submitted directly to the RCPCH for analysis.
- Data items required for the Specialised Services Quality Dashboards (SSQDs) are submitted from BadgerNet direct to the QSIS portal for analysis.
- Data is also submitted from BadgerNet to the National Neonatal Research Database (NNRD), which is maintained by Neonatal Data Analysis Unit, Imperial College London (NDAU). The NNRD is available to support audit, evaluations, benchmarking, quality improvement and a wide range of clinical, epidemiological, health services and policy research.

In addition to the above dataflows, data is collected separately for the National Maternity and Perinatal Audit (NMPA) to find out more about what factors in pregnancy or during birth might cause babies to need neonatal care. There is current interest nationally in developing a Neonatal Services Monthly Statistics dashboard along similar lines to the NHS Digital, Maternity Services Monthly Statistics,[174] this requires further exploration by the Neonatal CRG with NHS Digital.

[173] *https://datadictionary.nhs.uk/data_sets/supporting_data_sets/neonatal_critical_care_minimum_data_set.html*

[174] *https://digital.nhs.uk/data-and-information/publications/statistical/maternity-services-monthly-statistics*

Figure 48: Current dataflows for Neonatology using the BadgerNet platform



Source: GIRFT

Whilst it is not mandatory for trusts to use data from BadgerNet to support trust submissions to SUS and National Cost Collection (and not all trusts do), to date this has proved to be the most reliable system for this. As trust EPR and prescribing systems develop, there is a need to ensure that duplicate data entry is avoided as much as possible and appropriate interfaces are built between data systems to ensure seamless dataflows.

Accuracy of dataflows to SUS and National Cost Collection

Activity and submission against correct location

As outlined earlier in this report, there are five levels of neonatal critical care activity calculated daily using the Neonatal Critical Care Minimum Dataset (NCCMDS) which records the activities and procedures that occur over each 24-hour period and uses these to generate a specialist neonatal Healthcare Resource Group (HRG) code. Activity must be submitted under the following three facility types:

- Category 13: Neonatal intensive care unit.
- Category 14: Facility for babies on a transitional care ward.
- Category 15: Facility for babies on a maternity ward.

Table 12 below shows specialist neonatal critical care HRGs (2016) recorded under facility category 13 in BadgerNet and National Cost Collection (data submission directly from trusts) for FY 2018/19. This demonstrates that XA04Z, transitional care activity, is often being included under facility category 13 when this activity is actually occurring in transitional care or postnatal ward areas.

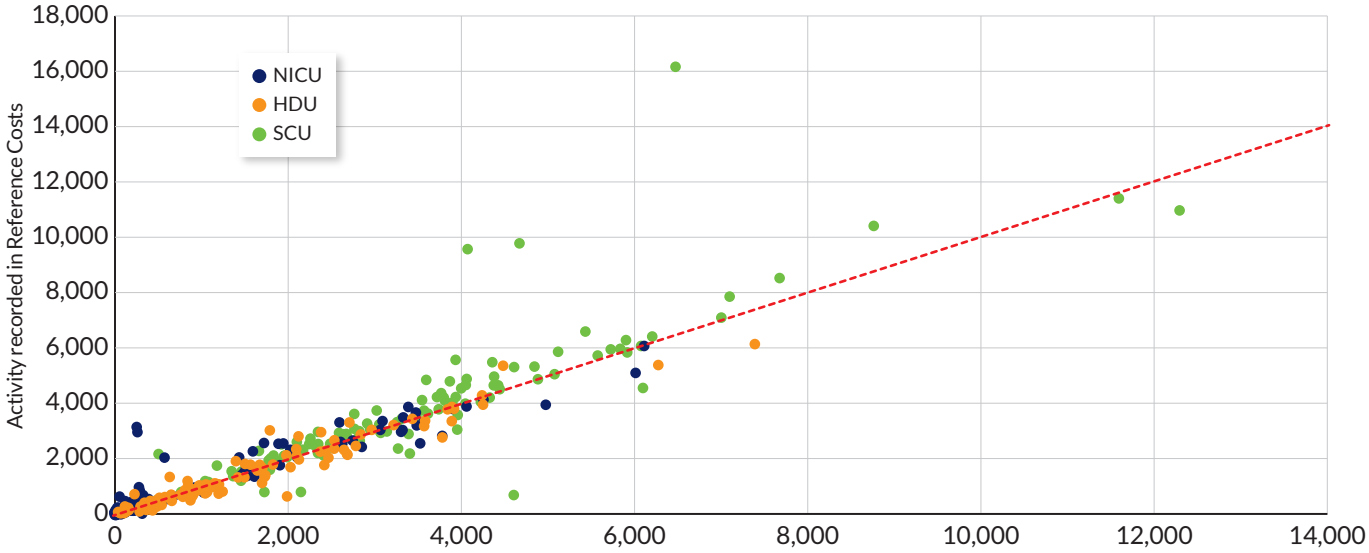
Table 12: Comparison of specialist neonatal critical care activity recorded under facility category 13

	BadgerNet	NCC
XA01Z – Intensive Care	139,472	143,223
XA02Z – High Dependency Care	193,504	169,908
XA03Z – Special Care (without external care)	451,702	460,366
XA04Z – Special Care (with external care)	29,240	136,334
XA05Z – Neonatology Supported Care	55,002	42,831

Source: National Cost Collection and BadgerNet, 2018/19

There is good overall correlation between total BadgerNet and NCC reported activity for XA01Z-03Z, but inconsistencies at individual provider level suggests there are a few units which could improve their data (**Figure 49**).

Figure 49: Correlation between BadgerNet activity and reference costs



Source: National Cost Collection, NHS Digital and BadgerNet

It was not possible to extract SUS activity data for direct comparison with BadgerNet and National Cost Collection activity data. However, comparative review of SUS and National Cost Collection data did reveal that in 2019, 14 trusts submitted costs to National Cost Collection (formerly known as Reference Costs) but did not submit anything to SUS. The use of BadgerNet data to support accuracy of trusts submissions to NCC and SUS was highlighted in a letter to all trust clinical leads by the chair of Neonatal Critical Care Expert Working Group (NCC EWG), National Casemix Office, NHS Digital in June 2020. It is hoped that this will improve accuracy of dataflows moving forward. In addition, a minor revision to the data flow in SUS to allow linkage of each neonatal HRG bed day to the location of care would further improve accuracy of the SUS data.

National Cost Collection weightings

Table 13 shows the relative weightings suggested in national cost collection guidance,[175] reflecting differences in resources required for the different HRGs.

Table 13: National Cost Collection weightings

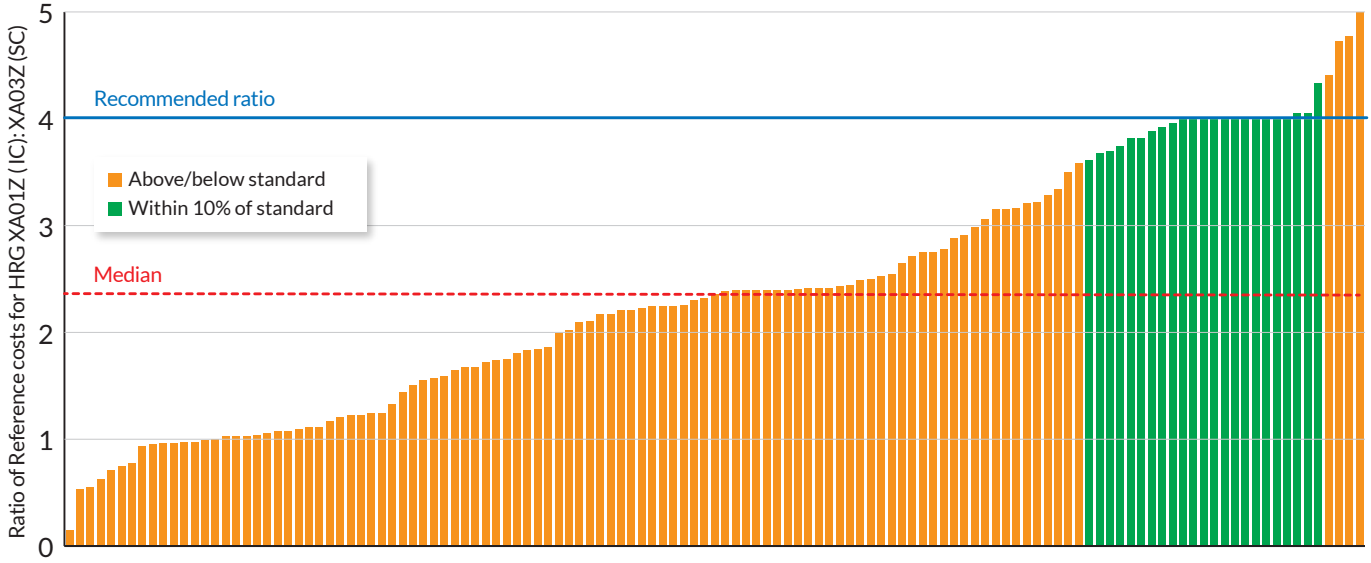
HRG code	HRG name	Relative weight
XA01Z	Neonatal Critical Care, Intensive Care	4
XA02Z	Neonatal Critical Care, High Dependency Care	2
XA03Z	Neonatal Critical Care, Special Care, without External Carer	1
XA04Z	Neonatal Critical Care, Special Care, with External Carer	0.8
XA05Z	Neonatal Critical Care, Neonatology Supportive Care	0.6

Source: NHS England and NHS Improvement

National Cost Collection data shows that these relative weighting are achieved in only a minority of units (relative weightings within 10% of recommended standard occurred in 29% of units for XA01Z: 02Z, 18% for XA01:03Z, 8% for XA01:04 and 5% for XA01:05Z) and varies widely across trusts (see **Figure 50** showing intensive care to special care ratios as an example), indicating that trusts are not allocating costs appropriately across the reference cost categories.

Moving forward it is important that trusts follow the guidance recommended in the National Cost Collection to improve accuracy of data collection. Patient-level costing submissions will start for the 2020/21 cost collection (commencing later in 2021) and will be mandatory for the 2021/22 cost collection exercise. These will improve the accuracy of costings including the relative costing differences between HRGs, as well as differences between units of different designations.

Figure 50: Ratio of cost between neonatal critical care HRGs XA01Z: XA03Z shown for all neonatal units



Source: Reference costs, 2018/19

[175] *www.england.nhs.uk/wp-content/uploads/2020/08/2020_02_28_NCCG_Vol_3_for_2020_Coll_Year.pdf*

Developments for neonatal critical care HRGs

Prices for neonatal critical care HRGs are negotiated locally leading to variation in prices paid to trusts for neonatal care and the potential for inequity in funding causing inequity in service provision and quality of care. This was recognised by the NCCR and the pricing workstream for the NCCR was run through Neonatal Critical Care Expert Working Group (NCC EWG), the National Casemix Office and NHS Digital, alongside the NHS England Finance and Pricing teams. This work culminated in development of suggested national non-mandatory benchmark prices for four unit designations (surgical NICUs, medical NICUs, LNUs and SCUs) which were published for consultation in November 2020 as part of the 2020/21 tariff.[176] Benchmark prices were finalised and published in the Section 118 Consultation as part of the national payment system 2021/22 in May 2021.[177]

COVID-19 has brought significant changes to pricing structures with most neonatal services moving to a block contract for FY2020/21, with extension into the first half of FY2021/22. Payment reform is underway, moving away from activity-based payment to aligned payments with incentives starting from 2022/23, comprising fixed and variable payments. This will be a radical change to how neonatal services are funded and will require careful planning with a slow changeover to ensure stability for services whilst also presenting opportunities for more flexible and innovative models of care across neonatology.

Any remodelling of the payment system relies on accurate data. Whilst much work has already been done on this in recent years to develop the non-mandatory prices, this work must continue and requires input from clinicians as well as trust finance and costings teams to ensure it is as accurate as possible.

Recommendations to improve data capture and reporting

Recommendation	Actions	Owners	Timescale from date of publication
20. Ensure seamless and accurate data flow of mandatory datasets for network pathways and flows, national and regional audit, benchmarking, research, pricing and national cost collections (NCC).	**a** Provide sufficient support locally (clinical and administration time) to ensure accurate data collection for the neonatal critical care minimum data set (NCCMDS), NNAP, and NMPA. With appropriate clinical job planning to support data checking and submission.	Trusts	Immediate and ongoing
	b Verify data accuracy and completeness in the annual NNAP data returns.	Trusts	Immediate and ongoing
	c Ensure accurate activity submission to NCC and SUS, and accurate cost submissions to NCC, with use of cost weightings included in National Cost Collection guidance. There should be evidence of clinician involvement in this process.	Trusts	Immediate and ongoing
	d Ensure, as EPR systems develop, that duplicate data entry is avoided with seamless dataflows for payment, costing, audit and research	Trusts, NHS Digital, NHSX	2 – 5 years
	e Explore development of a national Neonatal Services Monthly Statistics Dashboard along similar lines to the Maternity Services Monthly Statistics Dashboard.	Neonatal CRG, NHS Digital	12 months
	f Provide quarterly dashboards for key NNAP, maternity dashboard measures to support improvements in data quality, local benchmarking and improvements in NNAP measures.	Neonatal ODNs	6 - 12 months
	g Engage with trust level Patient Level Information and Costing System (PLICS) collection for neonatal critical care in line with national timetables.	Trusts	2 years
	h Agree an amendment to the data flow for SUS to allow linkage of each neonatal HRG bed-day to the location of care to improve accuracy of the data flow to SUS.	National Casemix Office, NCC EWG	12 months

[176] *www.england.nhs.uk/publication/national-tariff-payment-system-documents-annexes-and-supporting-documents/*

[177] *https://www.england.nhs.uk/wp-content/uploads/2021/02/20-21NT_Non-mandatory_prices.xlsx*

Procurement

In contrast to many other specialities examined under the GIRFT programme, neonatology does not have many high-cost consumables. However, there are some significant capital costs relating to specialised intensive care equipment required in all neonatal units regardless of their size. Infrequent use of this equipment in smaller units can create challenges and using the same model of equipment across a network can ensure that standardisation of equipment training is undertaken across the network. This also allows neonatal intensive care units (NICUs) and transport services to more readily remotely troubleshoot any equipment issues encountered in local neonatal units (LNUs) and special care units (SCUs) in their region. In this report, we have focussed on three areas where network-wide procurement, or standardisation, may improve care and reduce cost.

Parenteral nutrition

GIRFT key findings:

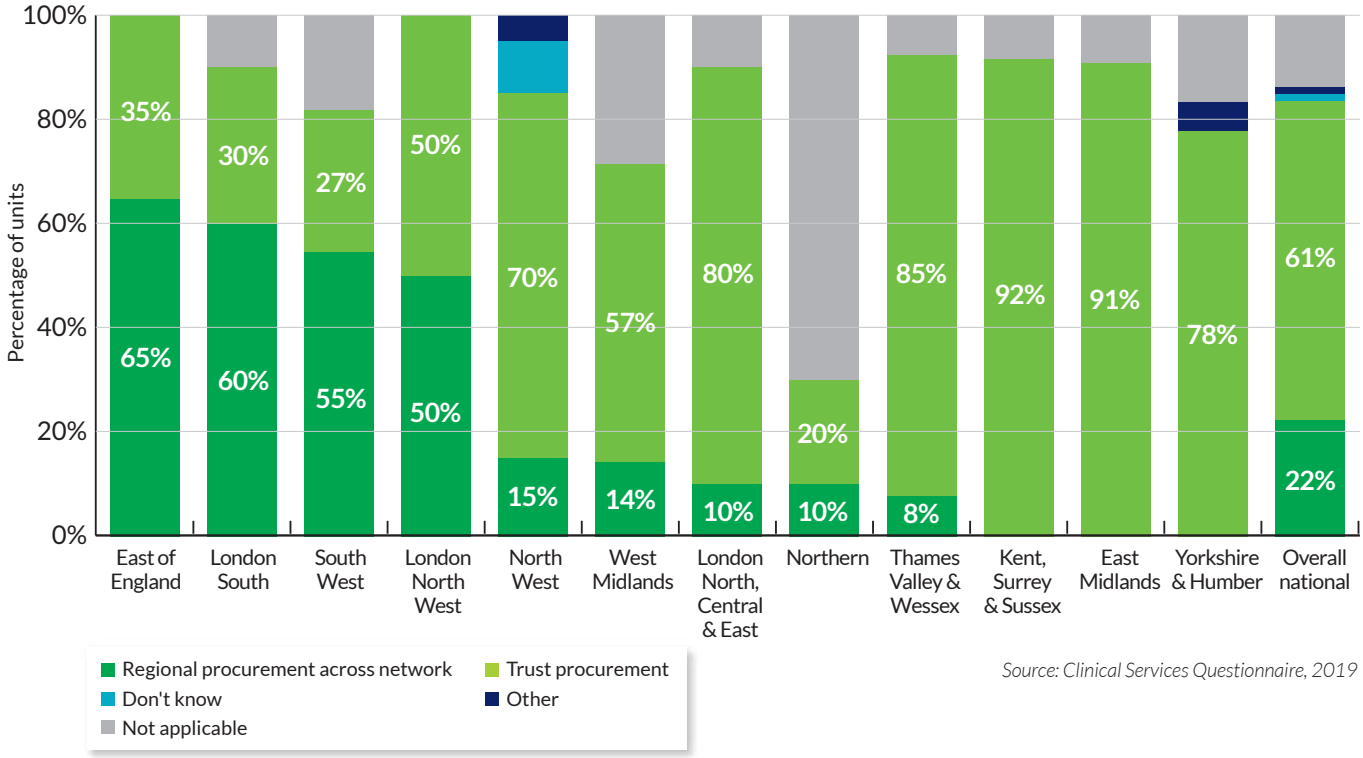
- 97% of NICUs and LNUs use standardised bags for initial and/or maintenance parenteral nutrition (PN)
- 116,000 PN bags were used in neonatal units in 2018/19
- 82% of PN bags are used in NICUs and 18% in LNUs

Parenteral nutrition (PN) is widely used in preterm infants due to immaturity of gastrointestinal function and should be started in the first few hours of life in very immature infants to prevent nutritional loss. NICE guidance recommends that all preterm infants <31 weeks gestation should commence PN as soon as possible after birth and within eight hours at the latest.[178] PN is also needed for some babies born at higher gestations who are sick or unable to tolerate enteral feeding. Standardised PN bags contain pre-formulated solutions which do not vary and are designed to meet the nutritional and clinical needs of these preterm babies, these are recommended for use in neonates (see drug standardisation). Bespoke PN bags are tailor-made for individual babies.

Nearly all units (97%) used standardised bags for either initial or both initial and maintenance PN, with approximately 116,000 bags used each year, 82% used in NICUs and 18% in LNUs (BadgerNet 2018/19). There are opportunities for standardising this across regions and this has been successfully achieved in East of England, South West and more recently across the three networks in London. **Figure 51** shows the variation across operational deliver networks (ODNs) in the procurement methods used for PN. A high prevalence of single-trust procurement suggests that there is potential for reducing costs through regional procurement, particularly for smaller volume users, as well as ensuring a high-quality product tailored to match neonatal nutritional requirements.

[178] *NICE (2020) NG154 Neonatal parenteral nutrition*

Figure 51: Parenteral nutrition procurement method for neonatal units within their ODN



Source: Clinical Services Questionnaire, 2019

IN PRACTICE

Procurement of total parenteral nutrition (TPN)

London neonatal ODN

In 2017 the London neonatal ODN and NHS England Specialised Commissioning collaborated on a Quality, Innovation, Productivity and Prevention (QIPP) programme to standardise the use of neonatal total parenteral nutrition (TPN) across the region. At the time of the QIPP the network had 23 neonatal units using bespoke TPN.

The aim of the QIPP was threefold: reduce variation in the preparation and delivery of TPN and improve safety; improve attainment; and reduce the cost of procurement through development of a London-wide procurement framework.

No funding for this QIPP was identified and network members undertook the QIPP supported by the ODN management in their own time.

The ODN convened a pan-London Core Neonatal Nutrition Group (CNNG) through expressions of interest which included medical and nursing representation from LNUs/NICUs, pharmacy, dietetics and initially NHS England Specialised Commissioning. The CNNG undertook initial benchmarking/scoping to help develop the pan-London case for change which demonstrated significant variation in practice and TPN formulation across the region, indicating the need for standardisation. Over the course of the next year the group agreed the formulation/prescription, and at every stage of its development the ODN consulted with all neonatal units using TPN. Once initial agreement was gained, the group developed pan-London guidance for the implementation of either the SCAMP or NEON formulation. These documents were consulted on by the wider ODN.

Alongside the development of the guidance, the ODN held stakeholder events across London to introduce the change and obtain feedback. The ODN had the full support of the London Medical Director for Specialised Commissioning, who was at stakeholder events to help embed implementation. The stakeholder events raised fears around change and potential unintended consequences, and it became clear that not all units would sign up to the London guidance in the first tranche of implementation. Some units with large aseptic units were producing their own in-house TPN and others were tied into long-term supplier contracts and were not willing to switch initially.

IN PRACTICE: Procurement of total parenteral nutrition (continued)

Following sign-off of the draft guidance the ODN facilitated scenario training exercises across the providers. The network also scoped out trusts who had developed particularly useful prescription sheets and these were adapted and circulated to all units to further standardise the process. The network leads were asked to be TPN champions across their patch, responsible for facilitating sign up to the guidance and linking in with local clinical leads/lead nurses to ensure unit-based training occurred.

At this stage the ODN then turned its attention to the pan-London procurement. With a requirement to follow EU procurement processes the ODN convened meetings with the London Procurement Partnership (LPP) and colleagues from their Medicines Optimisation and Pharmacy Procurement service to undertake initial meetings with interested suppliers and begin development of a pan-London procurement framework to drive down the cost of TPN and secure the required availability. Suppliers were invited to bid based on ODN requirements which raised a number of issues not previously considered, such as stability and its links to nutritional content and the type of bags to block out ultraviolet light. Guidance was updated to include these factors and the CNNG and ODN were invited along to view the bags and review tenders before settling on preferred suppliers and agreeing contracts, all handled by the LPP.

To close-off the development phase of the implementation, the ODN and NHS England jointly wrote to all neonatal units outlining their expectation that standardised TPN and the pan-London guidance be implemented at their trust by a given date. Trusts were asked to sign and return the letters as a signal of their acceptance.

It has taken a further two years for all trusts to sign up to the London guidance and regimen. This has been mainly caused by existing supplier contracts coming to an end, or trusts manufacturing their own at a lesser cost than the procurement framework contract. Only one trust remains an outlier at the time of writing (May 2021). The CNNG continue to meet to review clinical experience, management and attainment data based on their experiences to date. It may be necessary to make changes to the original prescription or procurement framework.

There was significant time required for both clinical and managerial staff with the project requiring several years to evolve due to consensus on the formulation taking some time and fears regarding clinical consequences of the change.

The ODN were concerned about use of a single provider in case of safety or supply concerns as there are a limited number of manufacturers. Some larger hospitals have their own aseptic units and manufacture TPN at a cost which is cheaper than the London procurement framework. There are major difficulties in calculating robust estimated/projected savings as neonatal TPN is included in the tariff price for the first 14 days.

Standardisation of formulation has minimised prescribing errors and clinical variation with less manipulation of licenced bags improving safety. Changing bag use to 48 hours instead of 24 hours can offer extensive cost saving and reduces risk of infection. Pharmacists report a large reduction in time spent on TPN as they are no longer prescribing bespoke formulations. A conservative estimated cost saving through bulk purchasing/and London Procurement Framework is c£150k/year per NICU. The framework standardised and drove down the cost of the bags.

Neonatal ventilators

NICE quality standards[179] for respiratory support soon after birth in preterm infants suggest that preterm babies needing invasive ventilation should receive synchronised volume-targeted ventilation as this reduces death, bronchopulmonary dysplasia (BPD) and risk of pneumothorax. GIRFT data showed that 4 in 10 neonatal units were not using this form of ventilation as their primary ventilation mode and it was clear from deep-dive visits that many units, particularly smaller LNUs and SCUs, did not have access to ventilators able to deliver this form of ventilation. Network support for neonatal units to change older ventilators and provide the same type of ventilator across all or part of a region may help to secure a lower overall price for the ventilators, but also assists with education across the region and troubleshooting from NICUs and transport services if there are difficulties encountered prior to patient transfer from LNUs and SCUs.

[179] *NICE (2020) QS193 Specialist neonatal respiratory care for babies born preterm*

Equipment for therapeutic hypothermia

Therapeutic hypothermia (TH) is an essential treatment for patients who develop hypoxic ischaemic encephalopathy in order to reduce death and improve neurodevelopmental outcomes.[180] BAPM has recently updated its Framework for Practice for TH and recommends that all units should be able to assess infants using amplitude integrated electro-encephalography (aEEG) and instigate TH using servo-controlled cooling equipment. [181] Whilst all NICUs have aEEG and servo-controlled cooling equipment, this is not the case for LNUs (cerebral function monitoring (CFM) 75% and active cooling 40%) and SCUs (CFM 26% and active cooling 2%).[182] Networks are responsible for coordinating staff training and ensuring consistent interpretation of aEEG across the network. Purchasing the same equipment across network LNUs and SCUs simplifies staff training and education and ensures transport and NICU staff are also familiar with the equipment being used and are therefore able to troubleshoot any equipment issues as well as support interpretation of aEEG findings.

Neonatal ODNs and network providers should agree a procurement framework across the Neonatal ODN, with a particular focus on PN, neonatal ventilators and equipment for therapeutic hypothermia.

IN PRACTICE

Time=Brain: Servo Control Cooling project

Kent, Surrey & Sussex Neonatal ODN

The Kent, Surrey & Sussex Neonatal ODN comprises four NICUs, three LNU and six SCUs. The project commenced in 2016 with the aim of improving prompt assessment and clinical diagnosis, reducing time taken to reach therapeutic cooling temperatures in babies with hypoxic ischaemic encephalopathy, enabling seamless cooling from LNU/SCU via the transport service to the NICUs. The following actions were taken:

- Guidance was drafted (including a patient information leaflet) and a training package was developed with roll out across all neonatal units to ensure all babies were appropriately assessed and managed in the initial period.
- A strong focus on ensuring clinicians were confident in establishing the diagnosis before starting active treatment and accurate documentation of the neurological examination.
- Purchase of the same equipment across most hospitals in the region (one unit had a different device). The type of device chosen to provide servo-controlled cooling was independently chosen by the trusts, but as they all wanted the same model, a bulk purchasing deal was agreed.

Eleven out of 13 neonatal units and all three transport services now have the same servo-controlled cooling equipment. It has supported training across the region and prevented swapping of disposable equipment and temperature changes when the baby is transferred by the neonatal transport service and again at the NICU. Following implementation audit data demonstrated better clinical knowledge and diagnostic assessment and much higher numbers of babies cooled to the correct temperature for therapeutic hypothermia within six hours.

Key barriers and concerns were:

- Clinician concern about increased numbers of babies being cooled with milder HIE – this did not occur.
- Concerns about cost – charity involvement usually addressed this.

Positive outcomes included:

- Nurses and some clinicians were delighted to be able to offer treatment in their hospitals, even if transferring out.
- Continuity of servo-controlled cooling across network pathway was advantageous.
- Structure and paperwork were helpful to provide reassurance, with regular network updates to ensure everyone was included.
- Training on equipment and nurse competencies was provided for everyone by the company and was straightforward.
- Focus on getting to target temperature within six hours is widely accepted.
- Documentation on neurological status has improved.
- The remaining neonatal unit is also now purchasing this same equipment.

[180] *NICE (2010) IPG347 Therapeutic hypothermia with intracorporeal temperature monitoring for hypoxic perinatal brain injury*

[181] *BAPM (2020) Therapeutic hypothermia Framework for Practice*

[182] *Mescall S, Dhamodaran M, Clarke P, et al (2021) Current availability of cerebral function monitoring and therapeutic hypothermia equipment in UK neonatal units and networks Archives of Disease in Childhood - Fetal and Neonatal Edition*

Recommendations for standardising procurement models to support neonatal care

Recommendation	Actions	Owners	Timescale from date of publication
21. Neonatal ODNs to work with local providers and agree procurement models, so consumables and devices used more infrequently are consistent across a network, the GIRFT 3-point strategy should be used to support this process.	**a** Agree a procurement framework across the Neonatal ODN, with a particular focus on parenteral nutrition, neonatal ventilators and equipment for therapeutic hypothermia.	Trusts with input from Neonatal ODNs, NHSX	2 – 5 years
	b Use sources of procurement data, such as SCS and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	GIRFT	Ongoing
	c Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	GIRFT	Ongoing
	d Use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Trusts, neonatal ODNs, GIRFT	Ongoing

Financial impact and opportunities

The greatest financial impact for neonatology will come from improving morbidity and mortality outcomes in neonates. This results in significantly reduced need for individuals to access health care systems during childhood and early adulthood as well as increasing their opportunity to contribute to the economy. These potential opportunity cost savings have not been quantified here but would likely be considerable over the lifetime of the child. Some examples are shown below that would likely lead to reduced longer term healthcare costs overall, after discharge from the neonatal unit (see chapters *Improving Clinical Aspects of Care*, *Clinical Governance*, *Safety and Litigation*, *and Supporting Families* for information on how these can be achieved):

- Improve attainment of antenatal and postnatal optimal start metrics for preterm infants.
- Improve early respiratory management which adheres to NICE quality standard QS193; *Specialist neonatal respiratory care for babies born preterm*.
- Improve early access to breast milk and sustaining the numbers of babies receiving breastmilk during their entire stay in the neonatal unit.
- Reduce unnecessary blood transfusion, donor exposure and adverse outcomes of transfusion in neonates.
- Adoption of universal Pulse Oximetry Screening.
- Improve family integrated care and psychological support for families.

Financial opportunities occurring within the secondary health care setting include whether whole, or part of a neonatal admission is necessary and in the best interest of baby and family.

Notional gross opportunities have been calculated related to two examples. If some babies with additional care needs born at term (37 weeks +) or late preterm (34-36 weeks) were managed in a different way, through improved neonatal community outreach and transitional care (per recommendations 4 and 15), neonatal admissions could be avoided or length of stay reduced. A notional opportunity has been estimated based on a number of assumptions (as set out in the table below). The calculated estimate indicates that managing these babies in a different way could free up to 12,400 cot days across all neonatal units in England (with an estimated 3,300 cot days being avoidable and 9,100 cot days shifting to transitional care). The associated cost related to this would be in the region of £8.3m.

Investing money to improve community outreach and transitional care services are required to achieve this saving. Any surplus could contribute towards the significant investment needed to support additional intensive care cots and optimising care pathways as well as improving and developing the neonatal workforce. Investment in these areas is essential to support networks and neonatal services to provide the best service configuration to improve survival, safety, and the quality of care for babies.

Table 14: Examples of notional opportunities

Improvement	National average	Notional activity opportunity*	Gross notional financial opportunity**
Reducing unnecessary mother baby separation for infants born at term *Recommendations 4 and 15* Opportunity = Reduction in term admissions to neonatal units through ATAIN, improved Transitional care and neonatal community outreach *Data: BadgerNet FY 2018/19* *Cost estimated based on average NICU HRGs (XA01,2,3Z) offset by HRG XA04 (transitional care) for transitional care element of calculation (19/20 national reference cost publication, uplifted to 21/22)* *Note: calculation assumes 2.9 days of avoidable length of stay per term admission***, with 1 day being potentially avoidable and 1.9 days being converted to transitional care*			
NICU	5.4% term admissions to neonatal unit as proportion of live births	4,400 cot days	£3.1m
LNU	4.3% term admissions to neonatal unit as proportion of live births	3,900 cot days	£2.7m
SCU	3.9% term admissions to neonatal unit as proportion of live births	1,400 cot days	£1m
Reducing unnecessary mother baby separation for infants born moderately preterm (34-36 weeks) *Recommendations 4 and 15* Opportunity = Reduction in moderate preterm admissions through improved Transitional Care and Neonatal community outreach *Data: BadgerNet 2018/19* *Cost estimated based on average less complex neonates bedday cost (HRG X03) LESS transitional care cost (HRG X04) (19/20 ref costs uplifted to 21/22 prices)* *Note: calculation assumes 6.5 days of avoidable length of stay per pre term (34-36wk) admission***, with 50% of these cot days converted to transitional care*			
NICU	1.27% 34-36 week (less complex) admissions to neonatal unit as proportion of live births	1,700 cot days	£0.9m
LNU	1.35% 34-36 week (less complex) admissions to neonatal unit as proportion of live births	700 cot days	£0.4m
SCU	1.81% 34-36 week (less complex) admissions to neonatal unit as proportion of live births	300 cot days	£0.2m
Total		**12,400 cot days**	**£8.3m**

Notes:

* Unless specified, activity that could be avoided is shown.

** Costing of financial opportunity: unless otherwise stated, cost estimates are based on published national average 19/20 reference costs https://www.england.nhs.uk/national-cost-collection/, uplifted to 20/21 using tariff inflation.

*** RCPCH NNAP data (national neonatal audit data) identifies that in 2019 the average number of days stay in neonatal units in England for term babies receiving special care where no oxygen is administered is estimated as 2.9 days on average and 6.5 days for pre term babies (34-36 weeks). https://bmjopen.bmj.com/content/bmjopen/7/5/e016050.full.pdf

About the GIRFT programme

Getting It Right First Time (GIRFT) is a national programme designed to improve treatment and care by reviewing health services. It undertakes clinically-led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal, they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after the pilot programme, it delivered an estimated £30m-£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model has been applied in more than 40 different areas of clinical practice. It consists of four key strands:

- a broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors;
- a series of discussions between clinical specialists and individual hospital trusts, which are based on the data – providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area of practice, in the context of the national picture. This then enables the trust to understand where it is performing well and what it could do better – drawing on the input of senior clinicians;
- a national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for improvement across the relevant services;
- an implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

GIRFT and other improvement initiatives

GIRFT is part of an aligned set of workstreams within NHS England and NHS Improvement. It is the delivery vehicle for one of several recommendations made by Lord Carter in his February 2016 review of operational efficiency in acute trusts across England.

The programme has the backing of the Royal Colleges and professional associations and has a significant and growing presence on the Model Hospital portal, with its data-rich approach providing the evidence for hospitals to benchmark against expected standards of service and efficiency. The programme also works with a number of wider NHS programmes and initiatives which are seeking to improve standards while delivering savings and efficiencies.

Implementation

GIRFT has developed an implementation programme designed to help trusts and their local partners to address the issues raised in trust data packs and the national specialty reports to improve quality. The GIRFT team provides support at a local level through the NHS England regional teams, advising on how to reflect the national recommendations into local practice and supporting efforts to deliver any trust specific recommendations emerging from the GIRFT visits. GIRFT also helps to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice. Through all its efforts, local or national, the GIRFT programme strives to embody the 'shoulder to shoulder' ethos that has become GIRFT's hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

Glossary

AHP
Allied health professional

AHSN
Academic health science network (NHS-led organisations that bring together health service, academic and industry members to improve patient outcomes and generate economic benefits by promoting innovation in healthcare)

ANNP
Advanced neonatal nurse practitioner

APCP
Association of Paediatric Chartered Physiotherapists

ATAIN
Avoiding Term Admissions in Neonatal Units programme

BAPM
British Association of Perinatal Medicine

BPD
Bronchopulmonary dysplasia

CDOP
Child death overview panel

CCG
Clinical commissioning group

CNST
Clinical negligence scheme for trusts

CRG
NHSE clinical reference group

DERS
Dose error reduction system

ENNP
Enhanced neonatal nurse practitioner

EPR
Electronic patient record

FMN
Fetal medicine network

HD
High dependency

HEE
Health Education England (a Non-Departmental Public Body. It supports the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place)

HRG
Healthcare resource groups - developed to characterise groups of patients with similar resource utilisation under payment by results (PbR)

HSIB
Health Safety Investigation Branch (conducts independent investigations of patient safety concerns in NHS-funded care across England)

ICS
Integrated care system (NHS organisations that, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS care, and improving the health of the population they serve)

IQR
Interquartile range

LNU
Local Neonatal Units provide short-term intensive care (1-2 days); and high dependency/special care and transitional care services for their local populations

MDT
Multidisciplinary team - a team of healthcare professionals from different disciplines

MRCPCH
Member of the Royal College of Paediatrics and Child Health

MVP/MNVP
Maternity Voices Partnership/Maternity and Neonatal Voices Partnership

NCC
National cost collection - formerly known as 'reference costs'. An annual return from each Trust that describes the costs of delivering care.

NCCMD
Neonatal Critical Care Minimum Dataset

NCCR
NHS England Neonatal Critical Care Transformation Review published December 2019

NICU
Neonatal Intensive Care Units (NICUs) provide intensive care for the smallest and sickest babies across the whole region, in addition to high dependency, special care and transitional care for their local population

NIPE
Newborn and infant physical examination – a screening programme that screens newborn babies within 72 hours of birth, and then once again between 6 and 8 weeks for conditions relating to their heart, hips, eyes and testes

NNA
Neonatal Nurses Association

NNAP
National Neonatal Audit Programme

NPPG
Neonatal Paediatric Pharmacy Group

NVP
Neonatal Voices Partnership

ODN
Operational delivery networks, which are focussed on coordinating patient pathways between providers over a wide area to ensure access to specialist resources and expertise

PMRT
Perinatal mortality review tool

PN
Parenteral nutrition

POS
Pulse oximetry screening

QIS
Qualification in specialty

RCPCH
Royal College of Paediatrics and Child Health

SCU
Special Care Units (SCUs) provide special care and transitional care for their local population

SUS
Secondary Uses Service - the central NHS data repository or 'warehouse' through which all hospital episode data should flow

TPN
Total parenteral nutrition

WTE
Whole time equivalent

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