Bliss Scotland baby report 2017

An opportunity to deliver improvements in neonatal care

Bliss Scotland
for babies born premature or sick


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NOT TO BE USED IN A VERTICAL POSITION

Contents

Acknowledgements

Bliss Scotland would like to thank the staff at neonatal units across Scotland and the Scottish Neonatal Transport Service who took the time to provide us with information for this report. We would also like to thank the parents who responded to our survey and shared their stories with us.

We are grateful to everyone who has given us invaluable advice and help with developing the survey questions and interpreting the results.

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Foreword

Every year, around 59,000 babies are born in Scotland. One in ten of these babies will be born premature or sick and will require lifesaving neonatal care to help them survive and thrive. Sadly, not all of them will make it home. The care they receive in their first few hours, days or weeks of life is vital for determining their chances of survival and long-term quality of life.

In light of the 2015 Morecambe Bay Inquiry and Montgomery Ruling, the safety of maternity and neonatal services has been increasingly under the spotlight, and it is welcome that the Scottish Government has recognised this as an important area of service development. In 2015 the Minister for Public Health committed to reviewing maternity and neonatal services to ensure every baby and mother gets the best possible care and to identify where improvements are needed in the future. Bliss Scotland has been pleased to be closely involved in this review, and we look forward to its imminent publication.

It is encouraging that there is such a clear appetite for improvement and development across neonatal services in Scotland – but the findings of this report reinforce the need for real urgency in delivering change. Our report reveals significant nursing and medical workforce challenges, and that neonatal units across Scotland are understaffed and under resourced now; this is putting babies at risk. Neonatal staff work tirelessly to ensure every baby receives the care they deserve and need, but they cannot do this without additional resources to enable services to meet national standards.

Parents must also be at the heart of their babies' care and decision-making, but our report highlights that far too many face multiple practical barriers which prevent them from being with their baby, such as a lack of free overnight accommodation. Future developments in neonatal care must therefore put a clear focus on delivering tangible measures which support parents to be with their babies.

The forthcoming publication of the Scottish Government's review of maternity and neonatal services provides a unique opportunity to deliver integrated and transformative change to this vital area of healthcare, and we urge decision makers to make the most of this opportunity – ensuring neonatal units have the staff and the funding they need to deliver safe, high quality services – so that all babies born premature or sick in Scotland have the best possible chance of survival and quality of life.

Caroline Lee-Davey
Chief Executive

Summary of findings

Evidence from neonatal units, the neonatal transport service and parents across Scotland has shown that the services providing life-saving care to thousands of babies are under significant strain. Neonatal care lacks the nurses and doctors needed to deliver safe, high quality care to babies born premature or sick.

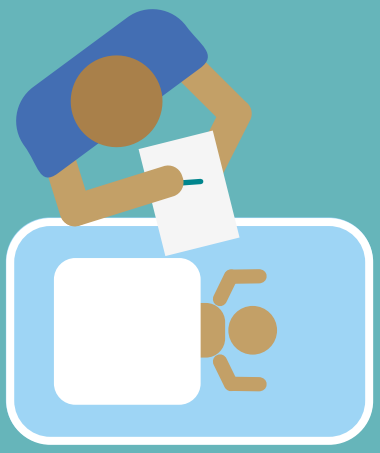
Our findings show that significant additional resources are needed to ensure the sustainability of the service. Investment into facilities and support infrastructure to keep parents together with their baby is also required to facilitate family-centred care, which is proven to be best for babies and their families.

We have found:

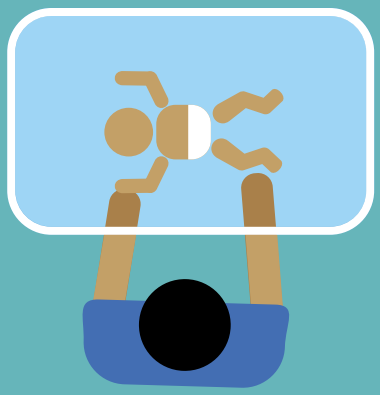
- Three quarters of units who provided information in our survey do not have enough nurses in post to meet minimum standards for providing safe, high quality care.
- 82 per cent of the nursing shortfall is due to insufficient funding.
- Ten out of 11 units identified difficulties with at least one aspect of nurse training and development.
- One third of units are unable to provide a community outreach service.
- Two thirds of units do not have enough medical staff to meet minimum standards.
- While the majority of units are able to offer parents access to a trained professional for psychological support, access is very limited at many units.
- Three out of 12 units have no dedicated accommodation for parents of critically ill babies, including two Level three units caring for the sickest babies.

Neonatal services under pressure

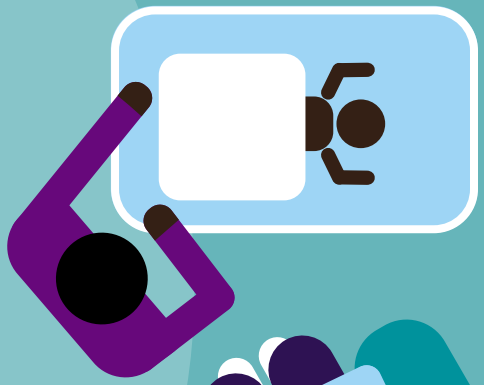
Only two out of 12 units
could support all parents with food and drink costs



Six out of eight units
do not have enough nurses in post



Ten out of 11 units
found it challenging to ensure their nurses received the training they need



Two thirds of units
do not have enough medical staff to meet standards

Over half of all units
do not have enough overnight accommodation for parents of critically ill babies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35.4

Introduction

Every year, 5,800 babies are born in Scotland who need specialist neonatal care to help them survive and thrive[1]. This means one in ten of all babies born in Scotland is admitted to neonatal care because they are born premature or sick.[2]

The care these babies receive while in hospital is crucial for both their survival and their long-term quality of life. While many of these babies will grow up to have no serious ongoing health conditions, some will face a range of complications in later life.[3] A high quality, appropriately staffed neonatal service is essential for ensuring that babies born premature or sick grow up to be healthy and able to reach their full potential. However, our findings show that many neonatal services in Scotland do not have the staff or resources they need to provide care in line with nationally agreed standards for safe and high quality care.

Babies born premature or sick are currently cared for in 15 neonatal units across Scotland. Three regional Neonatal Managed Clinical Networks (MCNs) exist to ensure that care across each network area is equitable and of high quality. A key part of the MCN role is to ensure babies are cared for at a unit appropriate to their needs, and as close to home as possible.

This report is based on information provided by 13[i] neonatal units and the neonatal transport service, ScotSTAR, which operates across Scotland. Parents across the nation also shared their experiences with Bliss Scotland. Please see the methodology for more information about how this research was conducted.

Why are babies admitted to neonatal units?

Over half (54 per cent) of all babies admitted to neonatal care in the UK are born at full term, but with an illness or condition that requires admission and treatment – this ranges from an infection or jaundice to congenital abnormalities and babies requiring surgery.[4]

46 per cent of babies require neonatal care because they are born premature, at under 37 weeks' gestation.[5] These babies are born before they are fully developed, and will often have the longest stays in neonatal care. In Scotland, approximately seven per cent of all babies are born premature, though not all of these babies will need specialist neonatal care.[6]

Quality standards

Neonatal Care in Scotland: A Quality Framework was published in 2013 by the Scottish Government, and sets out the range of services required to ensure high-quality care is provided to babies born premature or sick, and their families. Bliss Scotland worked as part of the Neonatal Expert Advisory Group to develop this vital document.

The Quality Framework draws on various existing standards documents, most notably the *Toolkit for High Quality Neonatal Services* (2009) and the British Association of Perinatal Medicine (BAPM) *Service Standards for Hospitals Providing Neonatal Care* (2010), and has been structured to be in line with NHSScotland's *Healthcare Quality Strategy* which determines that care should meet six quality dimensions, including being person-centred, safe and equitable.

i Several units only provided limited information in their survey response, particularly with regards to nursing data. This is why for some sections of the report statistics are based on fewer than 13 total responses.


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Nursing

Neonatal nurses provide the majority of care to babies who are receiving treatment in neonatal units. It is important that units in Scotland are sufficiently funded and resourced to maintain consistent nursing levels which meet nationally agreed standards, to improve the outcomes of all babies born requiring neonatal care.

Evidence

As early as 1993, research identified the key nurse-to-baby ratios required in neonatal care, which would then be incorporated into standards documents, including the *Quality Framework*. Williams et al. found, after asking nurses to provide a breakdown of how long they spent doing each task on their shift, that the most unstable babies required continuous attention from one nurse. One nurse could look after up to two ventilated babies, and a single nurse was able to care for up to four babies requiring special care.[7]

More recent studies have determined that nurse-to-baby ratios adopted within national standards should be regarded as minimum levels. Milligan et al. concluded that babies who were clinically stable and only in need of special care could require a significant amount of attention when establishing breast or bottle feeding, and a very unstable baby could require the continuous care of more than one nurse. They concluded staffing level standards should be regarded as minimum requirements.[8] Pillay et al. agreed, concluding in their study of a single neonatal network that "far from being aspirational, [the standards] are practically needed as the bare minimum for adequate service provision."[9]

Nurse staffing levels also directly correlate with mortality rates, with research showing that infants cared for in a setting with higher nurse-to-baby ratios have an improved adjusted risk for survival.[10] It is therefore vital that sufficient numbers of nurses are available on a unit, otherwise babies could be put at risk. The most recent research published in 2016 by Watson et al. established that an increase in mortality rates at Level three units occurred when there was a decrease in the required one-to-one nursing for babies receiving the most intensive level of care.[11]

As well as ensuring the overall nurse-to-baby ratios are sufficient, it is essential that enough nurses with the right skills are available on a unit. Hamilton et al. show in their 2007 study of 54 neonatal intensive care units in the UK that having more nurses Qualified in Speciality (QIS)[ii] than the standards recommend, reduced the risk of mortality by 48 per cent.[12]

National standards: nurse staffing

The *Quality Framework* sets out the nurse-to-baby ratios which should be maintained for the different levels of cot to ensure that all babies receive the care they need: there should be one nurse available for every four babies in special care, one nurse available for every two babies in high dependency, and one nurse for every baby in an intensive care cot.

All of these ratios are the minimum required to provide high quality care. Due to the individual care needs of each baby, some will need a higher nurse-to-baby ratio; particularly those receiving intensive or high dependency care

ii This is a nurse or midwife who holds a post-registration qualification in specialised neonatal care.

Three quarters of units (six out of eight) who provided sufficient information in our survey did not have enough nurses in post to meet minimum standards for providing safe, high quality care. It is of particular concern that four of these were Level three units which care for the sickest and most vulnerable babies. The only two units which had enough nurses in post were both Level three units.

> “ ‘There were times when there weren’t the required amount of nurses in intensive care. If there were ventilated babies it was supposed to be one to one but often wasn’t. You often overheard staff saying how they were struggling for the next shift or next day and were short staffed. ”
>
> (Mother of baby born at 28 weeks)

Neonatal units located in more remote regions were more likely to have more acute staffing shortfalls than units located more centrally, and also experienced additional pressures with recruitment with some respondents noting that their location could make it difficult to recruit.

Bliss Scotland calculates, based on the information provided, that at least an extra 74 neonatal nurses are needed across Scotland to ensure that all babies born premature and sick get the care they need.

For some of these units, the shortfall represents a significant proportion of their overall workforce. For example, one unit, which currently has 46 WTE (whole time equivalent) nurses in post, needs their workforce to increase by 30 per cent to meet standards – this is equivalent to an extra 14 nurses.

> “ ‘Although we have not closed either cots or the unit, nursing shortages (long term) create our biggest pressure. Staff regularly care for more babies than recommended by BAPM to ensure specialist referrals can be admitted and to accommodate our own labour ward activity. ”
>
> (Senior Sister)

The vast majority of this shortfall is due to units not being funded to employ sufficient nurses to meet the standards. In total, these units would still be falling short by 61 nurses if all their vacancies were filled – meaning that 83 per cent of the total shortfall is due to inadequate funding. All but two of the units which were falling short of staff would still not be meeting standards if all their vacancies were filled.

It is essential that as a matter of priority units are staffed appropriately to deal with their workload and that required funding is provided without delay to begin recruitment and training for the nurses that are needed now and into the future, particularly given that it takes at least five years to train a nurse to QIS standard in this highly complex area of care[iii].

iii Training a nurse to Qualified in Speciality status takes around five years in total. This consists of a nursing degree (generally three years), and then a minimum of six months’ experience working in a neonatal unit to be accepted on to the QIS training course. This post registration qualification then takes a further one to two years to complete.

Specialist nurses and nurse training

For babies to have the best chance of survival and quality of life, they need not only to be cared for by enough nurses, but by nurses with a high level of experience and competence to carry out very complex care for the smallest and sickest babies.

It is essential that neonatal nurses are able to maintain and develop their skills through regular training and development opportunities, appropriate for their role, to ensure that their skills are maintained against the most up-to-date guidelines and best practice.

National standards: specialist nurses and nurse training

The *Quality Framework* sets out that a minimum of 70 per cent of the registered nursing workforce establishment should hold an accredited post-registration qualification in speciality (QIS) for neonatal care. This standard is vitally important to ensure that a high proportion of the nurse workforce in each unit has this proven competence in providing complex care to these vulnerable babies.

The *Framework* also states that staff should have a high standard of knowledge and skills and that all staff providing direct nursing care should be supported to participate in continuing professional development of relevance to their role on the neonatal unit.

Bliss Scotland understands that neonatal units across the country are dedicated to maintaining a high level of QIS nurse staff. Bliss Scotland has even heard from units which aim to maintain a level of QIS of 80 per cent, setting their own unit best practice as higher than stated in standards. Health care professionals have also fed back to Bliss Scotland that units work hard to ensure that a constant stream of nurses are available to take up places on QIS courses. This highly specialist training, which is shown to reduce mortality rates, is delivered across two sites in Scotland, and the work which has gone into improving the consistency of the courses so that care is equitable at all units should be highly commended.

While this strong commitment to ensuring high numbers of QIS nurses throughout Scottish neonatal units must be warmly welcomed, our research has uncovered some challenges facing units in ensuring that their staff can access other types of both specialised and mandatory training, with more challenges on the horizon.

In order to make progress towards closing the neonatal nurse staffing gap in Scotland it is vital that sufficient resources are available to train and develop the existing workforce, as well as the workforce of the future. This will enable the development of specialist nurses in-house, relieving some of the pressure on needing to recruit nurses from overseas. Ongoing development and training opportunities are also important for nurses working at all bands to ensure that their skill set and expertise is maintained.

While the *Quality Framework* makes it clear that all staff should be appropriately supported to maintain their skills and access development, ten out of 11 units told us that they experienced some difficulties with ensuring their staff receive the training and development opportunities they need. This included every Level two and Level three unit which provided information.

The most common difficulty for units was being able to release nurses for training, with eight units, including five Level three units, struggling to meet training needs for this reason. One unit commented that this affected mandatory, as well as specialist, training and as such affected all nurses working at all levels. Existing staff shortages on units can make it impossible to back-fill staff. This results in some staff falling behind in their training, affecting their skills, or units relying heavily on bank or agency staffing to make up the numbers to release nurses from the unit, which is a costly and short-term solution.

Four out of ten units reported that lack of funding for training and development was a barrier, with a number of units noting that where funding for QIS and Advanced Neonatal Nurse Practitioner (ANNP) training was readily available, funding for other training was difficult to find. One unit noted that there is little opportunity to develop aspects of the service such as bereavement support.

> "'There is limited to no opportunity to relieve nurses for additional areas of training and service development such as simulation training or to develop the service in areas such as outreach to post-natal wards, transitional care or bereavement support."
>
> (Lead Nurse)

This is a particular concern because funding for QIS and ANNP training has in recent years been provided centrally from the Scottish Government through NHS Education for Scotland (NES).[13][14] However, this is soon to expire. From 2017, responsibility for funding QIS and ANNP training will revert to NHS Boards, which is where units are currently struggling to access funds from for other training courses.

Three services reported that at times there was a lack of opportunity to maintain skills. A Level three unit noted that during times of low occupancy it can be a challenge to support staff to gain the competencies they need for QIS training.

The *National Clinical Strategy for Scotland* recognises that NHSScotland as a whole faces a challenge in ensuring that there is a suitably trained workforce in place over the next five to ten years. This presents a significant medium-term challenge to ensure that services remain sustainable, as a large number of staff across many specialities will be retiring within the coming decade.[15] Some units expressed concern that this would be a serious challenge for them in the near future. One healthcare professional stated, unprompted, that 'This will be a concern in the next year as five trained experienced neonatal nurses have moved on (retirement and other opportunities) over the previous 18 months.' For this unit with less than 30 staff, this represents an 18 per cent decrease in workforce numbers which could apply significant pressure to the unit.

It is essential that NHS Boards address these barriers to training for the neonatal nursing workforce, especially in light of the worrying staffing gaps exhibited across the service and long-term staffing issues they will face in future because of the workforce demographic. It is also vital that, given the restrictions already noted by units in accessing funds for training, a commitment is given by the Scottish Government and NHS Boards to ensure sufficient funding for neonatal nurse training, when the changes in the funding of specialist nurse training take place in 2017.

> "Our students who are commencing QIS and ANNP training in September 2016 are the last to get central funding. From next year Boards will have to fund this from within."
>
> (Nurse Manager)

Community outreach

Leaving the neonatal unit with your baby is an exciting time for families – but it can also be incredibly daunting. It is the first time parents have to take full control of their baby's care without constant support from clinicians and reassurance from machines that everything is fine. Some babies will be discharged who still need extensive care at home, such as receiving tube feeds or oxygen, and parents need to be confident in using this equipment alone.

National standards: community outreach

The *Quality Framework* stipulates that all units should be able to demonstrate that they have the staff with appropriate training, knowledge and skills available to provide support in the community post-discharge, where this is required.

Community outreach is vital to provide ongoing support to families who need it, and can help ensure babies are able to leave hospital sooner and make a successful transition to being cared for at home.

> "When my daughter was discharged we met the community neonatal nurse who would come out to visit us. She was great and it was reassuring to have her come and visit and check her weight and SATs etc. when you have been so used to machines being there and reassuring you."
>
> (Mother of baby born at 28 weeks)

Despite all units being required to have a community outreach service in place, one third (four out of 12) did not. However, the only Level three unit without community outreach said that they have plans underway to introduce this, and the three other units stated that they are looking at ways to expand the level of provision that they currently have.

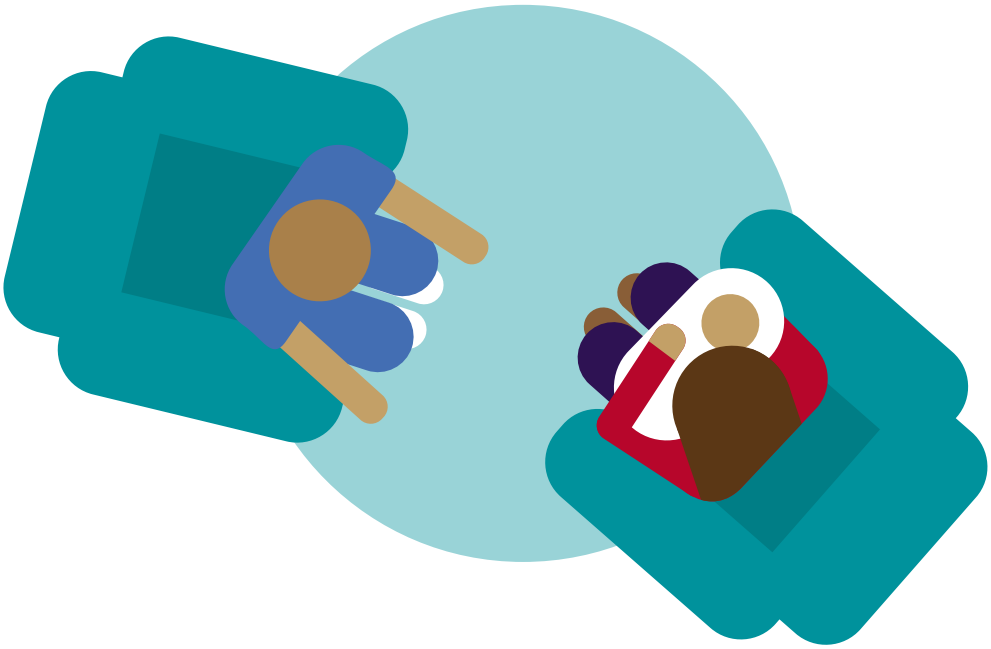
It is welcome that the majority of units have an outreach service currently in place, or in development. However, where it is in place, it seems that the service is often limited, with only two units able to provide more than one WTE member of staff to deliver the service.

> "I had very little support. No correspondence from the neonatal unit at all. I had to call my doctor's surgery after a week to ask for a health visitor to come to my home."
>
> (Mother of baby born at 34 weeks)

With around 20 per cent of the population living rurally, it is especially important that there is enough staff time dedicated to reach all those discharged to the community who need this support.[16] A well-resourced community outreach service is also required in urban settings to enable faster discharge of babies home.

Earlier discharge home, if babies and their families have a well-resourced community outreach team to support this, is not only better for babies and their families but for neonatal units too. It removes some of the burden on cots within units which in turn means babies are receiving costly hospital interventions for less time.

> “This is an area we would like to expand so that we can explore opportunity for more timely transfer home of babies and their families.”
>
> (Clinical Midwife Manager)



Medical staffing

Neonatal units need to have the right number and mix of medical staff in order to manage babies' care safely and effectively. It is very important that guidelines on the minimum number of medical staff are met. There are fewer medical staff than nurses working on neonatal units, so even one or two gaps on a medical rota can have a big impact on babies' care and how well the unit runs.

National standards: medical staffing

The British Association of Perinatal Medicine (BAPM) *Service Standards* set out guidelines for the minimum number of medical staff needed at each level of seniority.

All units: Medical staffing rotas should have a minimum of eight tier one (junior) staff members such as doctors new to the speciality and advanced neonatal nurse practitioners, eight tier two (middle grade) staff members such as speciality doctors and more experienced advanced neonatal nurse practitioners, and seven tier three (expert) staff members who are medical consultants.

The *Quality Framework* provides additional detail on how medical staffing rotas should be configured between each level of unit:

Level one: These units need 24 hour availability of a consultant paediatrician and out of hours cover is provided as part of a general paediatric service.

Level two: There needs to be 24 hour availability of a consultant paediatrician who has experience of and training in neonatal care, and out of hours cover can be provided by the general paediatric service. There should be 24 hour cover of resident experienced support with the ability to respond immediately to neonatal emergencies and 24 hour cover for provision of direct care with sole responsibility for the neonatal service. This can be either a member of medical staff, an ANNP or a QIS nurse who has undertaken extended training.

Level three: These units must have 24 hour availability of a consultant neonatologist whose duties, including out of hours cover, are solely on the neonatal unit. There should be 24 hour cover of resident experienced support for sole cover of the neonatal service and associated emergencies, and 24 hour cover for provision of direct care with sole responsibility for the neonatal service; delivered by either a tier one doctor or ANNP.

Shortfall in medical staff

Of the units which provided details, two thirds (eight out of 12) did not have enough medical staff to meet BAPM minimum standards for safe, high quality care. This included four Level three units and two Level two units. Further to this, a Level one unit reported having no tier two (middle grade) staff at all.

> "We didn't see a doctor during the full three week stay, all information and updates was conveyed by nurses."
>
> (Mother of baby born at 33 weeks)

Staffing shortages among the more experienced doctors was particularly pronounced. Three units did not have enough tier three (consultant) doctors on their rotas, and four units did not have enough tier two (middle grade) doctors to meet minimum standards for safety and quality.

It is particularly alarming to see these shortages of highly skilled doctors in Level three units, with four in total lacking sufficient medical staff at tier two or three. It is vital that these issues are investigated at a local level as a matter of urgency to address these gaps.

> “We were at two separate hospitals. Where they were born I cannot complain. However, after we moved, we never met our consultant – even though we had a nine week stay altogether!”
>
> (Mother of triplets born at 31 weeks)

Despite Level three units needing to have fully dedicated neonatal rotas, including out of hours, one unit had to partially share their tier two staff with paediatrics between 9.00pm and 9.00am. This is of concern because the babies being cared for in these units are likely to be most in need of specialist care and so need to be cared for by doctors whose time is dedicated to the neonatal unit, rather than dividing attention with other paediatric patients.

Adequate medical staffing is not only important to ensure the quality of the care, it is vital for communication and support for families too. Clear and regular communication with parents is essential to reducing their anxieties as their key questions and concerns can be addressed early, and is also crucial for ensuring that parents can be involved in decision making and caring for their baby.

> “The associate specialist is the only dedicated neonatal member of team and is clinical lead, however they are due to retire from post in early 2017.”
>
> (Doctor)

The Royal College of Paediatrics and Child Health's (RCPCH) 2015 *Facing the future* standards outline that in every unit in the UK parents should have a consultation on their baby's condition with a senior member of the team (either a consultant, tier two (middle grade) or an ANNP) within 24 hours.[17] However, the National Neonatal Audit Programme's (NNAP) 2016 *Annual Report on Data* found that this happened in units across Scotland on average only 75 per cent of the time – falling well below the 100 per cent requirement, and ranking second from bottom when measured against all neonatal networks in the UK.[18] As this is the first time Scottish units have contributed to an NNAP report, some of this shortfall can be attributed to data collection issues and inconsistent recording. However, it still provides a useful indicator that this is an area for focus and improvement.

Recruiting medical staff

A substantial barrier to units in Scotland providing care which meets national standards is their ability to recruit enough medical staff. Nearly all (ten out of 12) units which provided data had at least one unfilled medical vacancy, with tier one (junior doctors) and tier two (middle grade) positions proving particularly challenging to fill.

> “Recruitment to neonatal consultant posts has been difficult at times due to limited nationwide availability of appropriately qualified Certificate of Completion of Specialist Training (CCST) holders.”
>
> (Senior Nurse)

Several respondents commented, unprompted, that recruitment could be affected by geography. Some felt that the location of their hospital was affected by particularly high rents and living costs which put potential applicants off. Other respondents stated that the rural location of their site made it difficult to attract enough qualified staff to their area.

A further issue affecting the shortfall in medical staff is lack of sufficient funding to recruit the doctors and ANNPs that they need. Even if all medical vacancies were filled at the eight units which failed to meet minimum staffing levels, five would still not have had enough medical staff in place during the year 2015/2016 to meet BAPM standards.

Medical shortages in Scotland have been a long-term issue which have so far proved difficult to resolve, and this report demonstrates that these difficulties are still ongoing. The RCPCH 2015/2016 workforce survey found that in Scotland there was a ten per cent vacancy rate at tier one and an 11.8 per cent rate at tier two across paediatrics.[19] This is an increase on the previous 2014/2015 survey which found that Scotland had a vacancy rate at tier one of 7.6 percent and a rate of 10.8 per cent at tier two.[20] It is also of concern that at the time of the 2015 survey taking place none of these vacancies could be filled by a locum.[21] These are persistent challenges, and there are long-term issues with staffing and maintaining tier two staff to meet standards.

> “We have 1.5 full time consultant posts vacant and a recruitment problem. We would benefit from more dedicated time for neonatal care.”
>
> (Consultant Neonatologist)

Concern for their service is also increasing among clinicians, with 50 per cent of respondents to the RCPCH survey in 2015 saying they were very concerned that their service would not be able to cope during the next six months, compared to just 11 per cent the year before.[22]

A combination of different factors has led to a significant number of units across Scotland struggling to meet the minimum recommended requirements for medical staffing. It is of concern that other evidence from the RCPCH reports has demonstrated that the medical workforce has been under pressure for some time and that these issues remain persistent and unresolved.

Allied health professionals

A whole range of different professionals is required to ensure that every baby born needing neonatal care goes on to have the best chance of survival and quality of life. While neonatal nurses and doctors will provide the majority of care, a multi-disciplinary team including (but not limited to) occupational therapists, speech and language therapists, physiotherapists and pharmacists come together to provide a comprehensive assessment and care plan individualised to each baby's needs.

> "'The physiotherapist provided amazing treatment to correct our baby's head shape and support her development through positioning and handling. She also followed us up after discharge home so there was great continuity."
>
> (Mother of baby born at 25 weeks)

National standards: allied health professionals

The *Quality Framework* sets out comprehensive guidelines for involving a range of allied health professionals in the neonatal team. There should be a dietician, physiotherapist and/or occupational therapist, speech and language therapist and a clinical psychologist within the neonatal team.

As well as this, Level three units should also have access to a specialist neonatal pharmacist whose job plan contains identified and protected time for providing advice and support in neonatal pharmacy.

Our findings show that while all Level three units had access to the full suite of allied health professional services, much of this was by referral to an outside service only, and unable to meet the demands of the service. For example, only two out of seven neonatal intensive care units had dedicated access to dietitians, and the same proportion had dedicated access to an occupational therapist. Only three out of seven had dedicated access to speech and language therapists.

> "'None of these professionals came to speak with us or offer advice. I asked and was told it wasn't something the unit routinely provided."
>
> (Mother of baby born at 33 weeks)

Level one and two units have much less access to dedicated time with allied health professionals, with the majority of services accessed on an ad-hoc basis via referrals. Some units at this level commented that access was insufficient to meet demand.

> "We have access to all specialists but resource allocated to the service for anything other than pharmacy and radiology is probably not optimal in terms of available sessions."
>
> (Neonatal consultant)

Several units noted that the dedicated time professionals had in their work plans for neonates was limited, and others noted that they still had to use a referral service even though they had dedicated access to professionals.

It is important for allied health professionals to have sufficient time with the neonatal service so that they become integrated within the team, and can influence how it works. These professionals need to be available to all babies on the neonatal unit, and not just those who are extremely premature or very sick.

If babies are unable to receive support from the full range of neonatal professionals when they need it, it can have a lasting impact on their long-term development and health. For example, poor nutrition or pain management can have a significant impact on their neurodevelopment as they get older.[23 24 25] An assessment by a multi-disciplinary team prior to discharge can help families overcome difficulties, such as feeding issues, which may reduce a baby's care needs and prevent further hospital admissions later on.

While it is positive that the majority of units can access allied health professionals, even if just through referral, it is clear that health professionals are concerned that this provision is inadequate. It is essential that Health Boards together with MCNs reassess the current provision and put plans in place to ensure there is sufficient allied health professional support to meet the need of the local population at each unit.

> "As a stand-alone (unit), access to neonatal specialty AHP services can be challenging. Work is ongoing within the region to explore whether access to such specialist services could be provided on a regional or MCN wide basis."
>
> (Department manager)

Occupancy levels

A consistently very high occupancy rate of cots has been shown to have a negative impact on babies' survival rates, with studies showing that babies cared for in an intensive care unit at 100 per cent occupancy had about 55 per cent higher risk of dying than babies admitted to units with lower occupancy.[26]

National Standards: occupancy levels

The *Quality Framework* provides limited guidelines for what occupancy levels units in Scotland should be operating at. Nursing establishment is calculated against activity based on an 80 per cent occupancy rate, which is higher than levels recommended by BAPM, but no further guidance is given on this issue.

BAPM states that services should be planned for an average occupancy of 70 per cent and the Toolkit explicitly states that average occupancy should not exceed 80 per cent.[27 28] Just as over-occupancy can stretch staff time and put inordinate pressure on units, a unit which is consistently running at low occupancy runs the risk of staff not looking after enough babies to maintain their skills.

While the average total occupancy level across all levels of care in units across Scotland was 75 per cent, this masked wide variation. This is resulting in a number of units caring for far more babies than is considered the safe level, while in some units staff are potentially not caring for enough babies with complex needs to maintain their skills.

> "Twice my baby was transferred to the less dependent ward due to more ill babies arriving in the unit. There were three wards and we were in there 14 weeks. I saw a lot of babies shuffled around in order to admit sicker babies."
>
> (Mother of baby born at 29 weeks)

As *Figure One* shows, units across Scotland are currently experiencing the greatest pressure with their high dependency cots, with two thirds of units (six out of nine) reporting a high dependency occupancy rate of over 80 per cent and three of these with an occupancy rate of over 100 per cent. One Level three unit also had a very high occupancy level of their intensive care cots, averaging at 97 per cent over the year.

The most significant problem for Level three units is very low occupancy of their intensive care cots. Two thirds (four out of six) of intensive care units had occupancy rates for their intensive care cots of below 70 per cent, and three of these units had an average occupancy rate of below 60 per cent. In order to maintain their safety and efficiency, neonatal care services should be planned for an average occupancy of 70 per cent.[29 30] It is particularly important that Level three units maintain an average occupancy in line with national standards to ensure that staff have enough clinical exposure to very sick or very preterm babies to maintain their skills.

The units with low occupancy rates across their intensive care cots also exhibited over-occupancy in different areas. For example, one unit with 57 per cent intensive care cot occupancy had a special care cot occupancy exceeding 135 per cent. Another unit with a 37 per cent intensive care cot occupancy rate had a special care cot occupancy of nearly 95 per cent.

This suggests that these units are regularly reassigning their cots to cope with the high number of babies who need a less intensive level of care. As a result, the intensive care cots they have been commissioned are utilised for other purposes, suggesting poor service planning

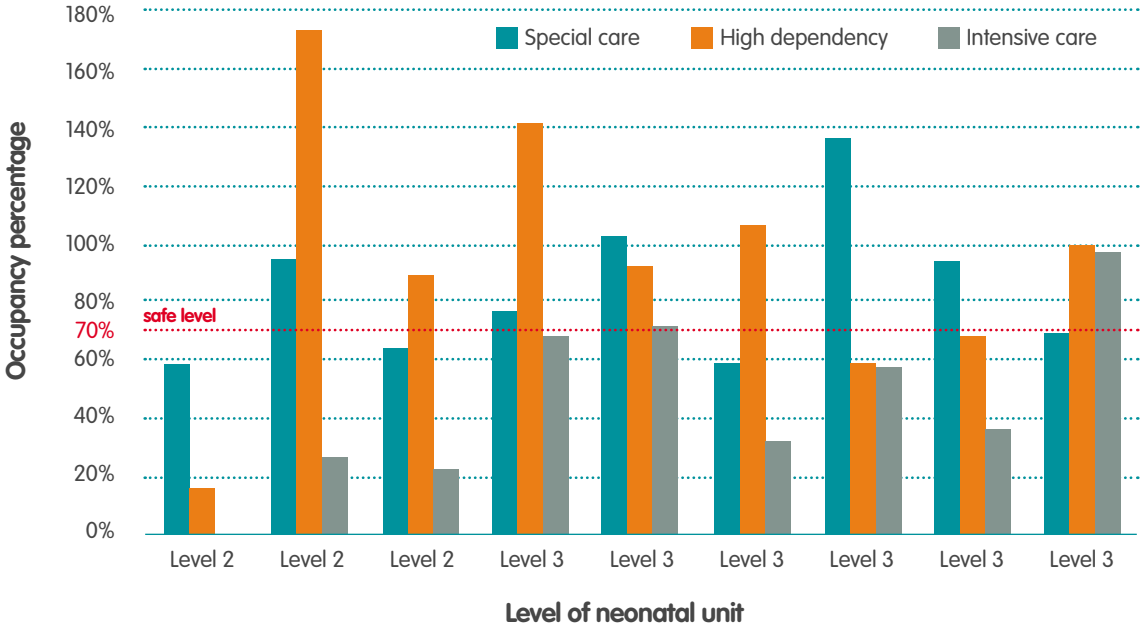


Fig.1 Average occupancy of neonatal units in 2015/2016 by category of care

Scotland has a large number of neonatal intensive care units in relation to its total number of units, with nearly half being designated at Level three. The low intensive care cot occupancy coupled with high levels of special care or high dependency cot occupancy exhibited at some of these units indicates that there are some problems with the distribution of resources across Scotland. It is vital that this is addressed to ensure that all neonatal units have the correct amount and mix of staffed cots so they are able to meet the needs of all the babies they care for.

Neonatal services have developed over time in Scotland rather than being specifically designed to meet the needs of babies and their families today, which has contributed to the high number of Level three units. The *National Clinical Strategy for Scotland* shows that 98 per cent of Scotland's land mass is rural, and is home to a fifth of the population. The rural population is the fastest growing in Scotland and until now many specialities, not just neonatal care, have evolved to meet local access needs to services, as opposed to being specialist hubs.[31] As a result, in many areas the population size is insufficient to sustain specialist services.

Clinical best practice stipulates that the very smallest and sickest babies have improved mortality and morbidity outcomes if they are cared for within a smaller number of highly specialist hubs. Staff at these hubs will be able to more easily maintain and advance their skills as they will be caring for more very sick babies than they would be at a smaller unit.

These findings indicate that the Scottish Government should take stock of the current service design and assess it to see whether it is currently set up to provide optimal care to the very smallest and sickest babies which are cared for by the service.

Cot closures

Sometimes units have no option but to close their cots (not use cots which are physically available) or close their unit to new admissions altogether, as a method of coping with demand or staffing issues. Five units provided details about the numbers of cot closures they experienced, which totalled 208 days throughout the year.

> “Cot closures used to be rare but they are becoming more common and is associated with pressure on staffing. Badger cot register is being piloted and will have record of closures in recent months and ongoing.”
>
> (Doctor)

11 out of 12 units told us they commonly had to close some of their cots, even though most did not have available the exact numbers of days that they were closed for. *Figure Two* reveals the different reasons reported by units for needing to close their cots. Nine units said they had issues with short-term nursing levels which affected the availability of their cots, with one respondent commenting, unprompted, that cot closures used to be rare but were becoming more common because of pressures with staffing. Five units stated that over-capacity issues led to cot closures, and one unit noted they had a lack of ventilators, and no funding to buy more, which led to them closing cots.

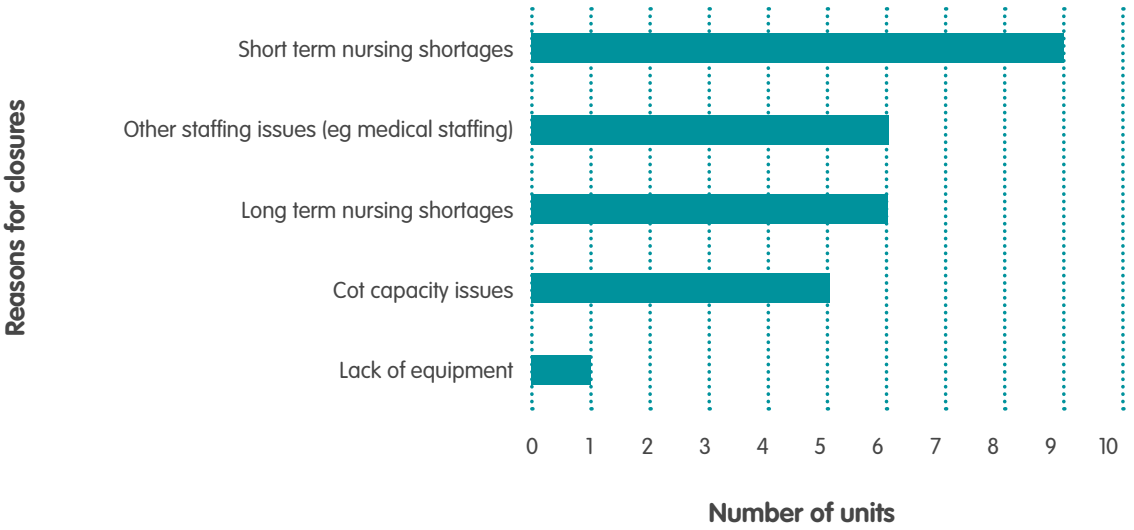


Fig. 2 Common reasons for cot closures

As *Figure Three* below demonstrates, nearly all units said there was more than one factor at play in their unit which contributed to cot closure. Multiple factors were particularly apparent at Level three units, where some units reported as many as four different reasons for needing to close their cots.

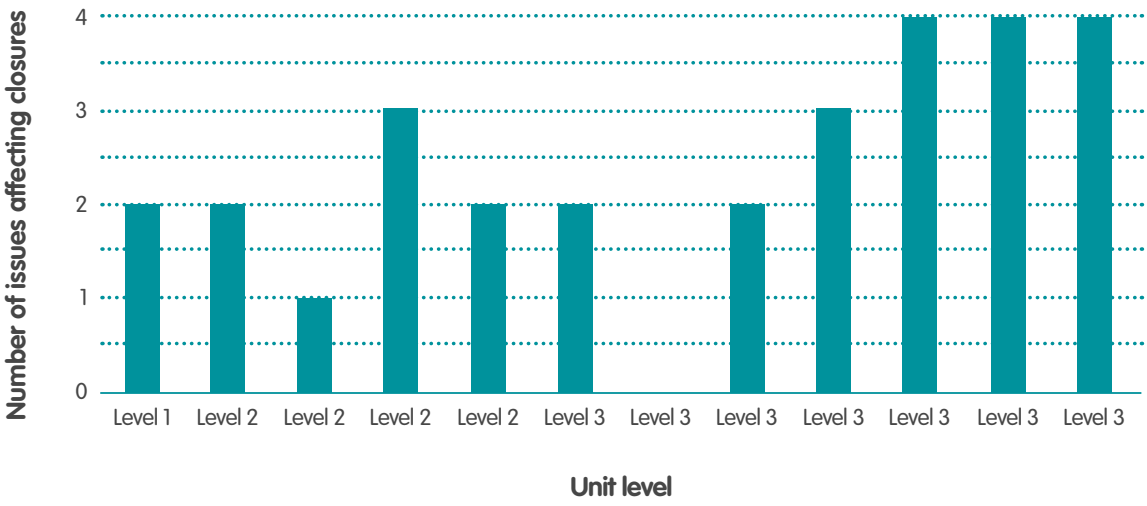


Fig. 3 Number of different reasons for cot closures per unit

There are significant and multi-faceted challenges facing units which are resulting in them needing to close cots to try and maintain a safe service. It is clear that investment in staffing and capacity is needed, and it is imperative that NHS Boards work closely with MCNs to ensure units are sufficiently resourced to cope with demand and limit closure episodes, which add to the distance families need to travel and put increased pressure on other areas of the service (see page 28).

> “Peak acuity periods can mean closing to admissions due to being over capacity in intensive care and high dependency.”
>
> (Senior Nurse)

Avoidable admissions

A significant pressure on neonatal services in Scotland is the admission of babies to neonatal units who could be more appropriately cared for in a different setting alongside their mothers. There is wide variation in the number of babies admitted to neonatal care in Scotland who were born at full term and do not have serious birth defects or disorders (congenital malformations). Although some of these babies are very sick and do need to be admitted to neonatal care, big differences in the number of full term babies admitted highlight inconsistencies in practice.

Six units provided information about their full term admissions; five were Level three units and one was a Level two. At these units, the proportion of babies admitted to the unit at full term without any congenital abnormalities ranged from 39 per cent to 60 per cent.

Unnecessary admissions put extra strain on neonatal units, as their cots are filled with babies that do not need such intensive treatment, contributing to problems with over-capacity and staff caring for more babies than is considered safe.

For families, this causes unnecessary stress and anxiety and can have a negative impact on babies and their parents. Ideally, babies that need a small amount of extra support, such as with feeding or maintaining their temperature, should be cared for in transitional care. Here, they will be kept with their mother who will provide the care they need with the support of midwifery and neonatal nursing staff. As a result, transitional care can avoid babies being admitted to special care and avoid the traumatic separation of mother and baby.[32]

There is extensive work occurring elsewhere in the UK to reduce avoidable term admissions, including through the development of additional post-natal and/or transitional care facilities where mother and baby can be cared for together.[33] This has the potential both to avoid unnecessary separation of mother and baby and to alleviate pressure on neonatal units. We would support the adoption of a similar approach in Scotland, with appropriate resourcing of facilities and staffing across both maternity and neonatal workforces.

Transfers

Neonatal transport is an essential part of the wider neonatal service. Dedicated and highly-skilled transport teams work across Scotland to ensure babies are cared for in a hospital appropriate to their needs and as close to home as possible. ScotSTAR (Specialist Transport and Retrieval) provides a national service for the transfer of some of the country's sickest patients, and is responsible for the Scottish Neonatal Transport Service. This single service operates across all three MCN areas.

The neonatal transport team has dedicated access to a road vehicle for routine use, and ad-hoc access to frontline ambulances if the dedicated vehicle is unavailable. As well as this, the team can access fixed wing and rotary wing aircraft. This provision is particularly important for Scotland – evidenced by the transport team completing more than one air transfer every week just for neonates.

National standards: neonatal transport

The *Quality Framework* states that there should be the provision of a single point of telephone contact through a dedicated line on which cot and maternal bed availability can be accessed and activated at all times. A high quality service should demonstrate timely provision of clinical care, minimised delays in emergency transfers and a sustainable transport infrastructure to support the service.

The pressures of capacity across neonatal services in Scotland place additional stress on the transport service. In the 2014/2015 financial year, 39 babies were transferred due to a lack of capacity at their neonatal unit, 20 of which were of extremely ill babies.[34] This adds to the workload of the service and carries a risk of interfering with the teams' ability to undertake emergency transfers in a timely manner.

When babies are moved due to lack of capacity rather than clinical need, this also adds unnecessarily to families' stress and worry as their baby is transferred to a new and unfamiliar unit. It often results in babies being even further away from home and means parents have to leave behind staff and other parents they have got to know.

> "Now this was terrifying for me, I was told on the morning of the day of the transfer 'it will happen any time now, just waiting on an ambulance' time went on, I stayed past dinner time not wanting to leave his side so I could be there for the transition, then it got to say about 8.00pm and the team told me they would have to wait till tomorrow, it would happen the next morning so I was to go home and rest… midnight I get a call to say they're transferring him there and then without me being able to get there in time. I was a nervous wreck."
>
> (Mother of baby born at 29 weeks)

Bliss Scotland understands that it is recognised across Scotland that there is a need for improved coordination and management of activity across the country. The transport team is involved with this and has been working with the Network Leads to develop systems and put them in place. Ongoing management and coordination of perinatal capacity and transfers on a national basis is likely to require further investment for the transport service to adequately address this need without compromising other areas of their service.

One of the most significant challenges facing the transport service is regarding recruitment and retention of staff. The service noted in response to our 2014/2015 survey that there are a very limited number of people with relevant expertise, and that this is set within the context of wider recruitment challenges across the whole of neonatology in Scotland.

> “Our biggest challenge is ongoing recruitment and retention, with unfilled nursing posts in the North team, ANNP/fellow and consultant vacancies in the West and East.
>
> Another area that we are working on is the expectations of transport when it comes to capacity management across the country. During periods of high cot occupancy across Scotland I am concerned about the potential impact that frequent calls to the on duty consultant may have on their clinical work.”
>
> (Consultant Neonatologist)

Despite persistent challenges with recruitment and retention of staff, and the pressure that capacity transfers create, there has been some significant and welcome progress since we surveyed the service in 2015, which informed the Bliss UK-wide *Transfers of premature and sick babies* report. Most significantly, the service has successfully transitioned from operating as three separate regional teams to one single service under ScotSTAR.

As a result, a single contact line has been established for neonatal transfers since July 2016, meaning the service meets *Quality Framework* requirements in this respect. The considerable recruitment and process development challenges that have been overcome to achieve this success should be commended. It is important that a single, dedicated line exists to ensure that transfer calls are dealt with quickly and efficiently.

During the snap-shot week our 2014/2015 survey asked about, all planned activity was provided by the neonatal team, and the service experienced no gaps on rota.[35] Currently, the service has three transport teams operational for 24 hours for half of the week, and two transport teams for the other half of the week. During periods where only two teams are operational, the whole of Scotland is still covered and transfers from any neonatal unit responded to as usual. However, this does suggest that additional resourcing should be provided to ensure that all three teams can be operational at all times.

Neonatal transport plays a significant role in ensuring that babies receive the care they need as close to home as possible. It is vital that the pressures caused by managing capacity and the ongoing difficulties with recruitment are addressed as a matter of priority.

Support for families

While medical intervention is essential for babies admitted to neonatal care to survive and thrive, a baby's parents and wider family are the single most important influence on their life. For babies, and their families, to have the best possible outcomes it is essential that parents are able to be with their baby for long, uninterrupted periods of time in order to take the lead in delivering their care.

Evidence

While there have been huge strides made in medical care for babies born premature or sick over the last 20 to 30 years, leading to more babies than ever before surviving to go home to their families, it is only relatively recently that the role of the baby's family in their care has been seriously studied to see how this impacts on a baby's outcomes and quality of life.

In 2009 parents and neonatal units in England took part in the Parents of Premature Babies (POPPY) Project which assessed what facilities were available on neonatal units and how supported parents felt they were to be involved in their baby's care. The POPPY Project defines family-centred care as "health professionals actively considering how it feels for parents to have a premature or sick baby, and working within a policy framework to improve the family's experience. This means being willing to "stand in the shoes of parents."[36] The study revealed that the neonatal journey could be traumatic and left parents lacking confidence in caring for their baby if they had not been facilitated to take the lead in their care in hospital. The report concluded that every unit should adopt a family-centred approach.[37]

More recent studies have explored how this approach can improve outcomes for babies. Kaffashi et al. concluded from their study monitoring sleep patterns - between babies who received significant skin-to-skin care and those who did not - that those who did had far better sleep episodes and significantly better brain development as a result.[38] Similarly, greater parental involvement in their baby's care has been shown by other studies to support brain development and improve cognition.[39] Other benefits have also been shown to include improved breastfeeding rates, as mothers are supported to be on the unit more consistently, making it easier to establish breastfeeding, earlier discharge from hospital, and reduced re-admission rates.[40 41]

With this growing body of evidence, a new approach called family-integrated care is developing which facilitates families taking the lead in their baby's care. Spearheaded in Canada, parents commit to spending at least 8 hours a day with their baby. They are fully supported with free accommodation, meals and transport and are also trained to carry out basic care such as administering naso-gastric feeds. Parents are also involved in all ward round discussions for their baby, and fully participate in decision making. This has been shown to improve parental confidence, communication between parents and professionals, and parents feeling closer to and more able to cope with caring for their baby outside of the hospital environment.[42]

For parents, being heavily involved with their babies' care also allows them to develop the skills and confidence they need to be able to take care of their child once they are home.

National standards: family-centred care

The *Quality Framework* states that a high-quality service will make dedicated facilities available for parents wherever possible. This should include having access to hot drinks outside normal hours, and a list of local accommodation options near the hospital with agreed rates provided.

The *Quality Framework* also states that any future design for a neonatal unit should be planned to provide 'several' overnight parent accommodation rooms onsite, 'in line with predicted need in the region and located a ten-15 minute walk from the unit'.

Accommodation and meals

Providing sufficient overnight accommodation to meet the needs of families is a challenge for neonatal units across Scotland. Three out of 12 neonatal units have no dedicated accommodation for parents of critically ill babies. Two of these units are Level three, caring for the smallest and sickest babies, who often require the longest stay; one of these reported that accommodation can only be provided in an emergency, and the other that their rooms were for rooming-in only[v].

> "It devastated us both financially and mentally. We were given a discount of £3 a day for parking but this soon adds up as we were in for five weeks. I got two nights' accommodation but was really ill after having my son and could not manage to look after myself. After that I had to leave as they needed the room. It absolutely broke my heart having to leave him in hospital. I couldn't drive after a C-section and had to be driven daily the 70 mile round trip to visit him. We were never given any help with meal vouchers or a discount card and so with petrol, parking and food ran up lots of debt while my son was in neonatal."
>
> (Mother of baby born at 30 weeks)

Unlike in Wales and England, where standards outline that there should be a minimum of one overnight room for parents per intensive care cot, the *Quality Framework* lacks clarity on the provision that is expected of units and Health Boards. And as Bliss found in a 2016 report on neonatal services in Wales, the one room per one cot standard was not enough for certain settings, particularly in rural and hard to reach areas,[43] which may also be true for the neonatal units in Scotland serving the most rural populations.

Work is underway at NHS Board level to improve access to parent accommodation.[44] However, Bliss Scotland believes that clear national standards are required which set out clearly how much overnight accommodation should be provided as a minimum to facilitate high quality family-centred care.

Using the Welsh and English standard of one overnight room per intensive care cot, our findings show that six out of ten units,[45] including four Level three units, in Scotland are unable to provide accommodation for all parents of babies in this very critical condition. While nine out of 12 units in Scotland are able to provide some overnight accommodation to parents, it is clear that provision is not enough to meet the needs of families using their services.

iv Rooming-in should be offered by the hospital to all parents before their baby is discharged. This allows parents to stay in a room on or near the unit and care for their baby overnight for a few days. This can help give parents confidence in caring for their baby alone while the unit staff are still available to help if necessary.

Many families will also have to travel a great distance to the hospital, even if their child does not need such intensive care and is admitted to a local unit. For those located rurally, 'local' units can in reality be far from home and accommodation should therefore be provided to meet the needs of the units' catchment populations so that all parents can be fully involved in their baby's care.

Nearly all (ten out of 12) neonatal units were able to meet the *Quality Framework's* very basic requirement that parents should be able to access hot drink making facilities outside of normal hours. However, four of these units have no facilities for families to warm up food or prepare simple meals. The cost of meals can be a significant barrier to families, adding an extra £61 on average to a family's weekly expenses,[46] and also forcing parents to cut their visits short just so they can go home to eat.

> "We spent over £2,000 in four months on parking and meals while trying to stay with our baby as she was struggling."
>
> (Mother of baby born at 27 weeks)

One unit which was unable to provide hot drinks to families in line with the requirements of the *Quality Framework* was a neonatal intensive care unit.

While two thirds (eight out of 12) of units said they could support parents with food and drink costs, either through meal vouchers, discounts for hospital canteens or providing free hospital meals, six of these units could only provide this to parents who were staying overnight on the unit. This means this support will be out of reach for many of the families who could benefit from it.

Evidence is clear that parents need to be supported to play a primary role in delivering their babies' care in order to help them achieve the best possible outcomes. This requires a shift in approach and practice to put parents at the heart of their babies' decision-making and care, and must be embedded into all neonatal units across Scotland. However, for parents to truly be partners in decision-making and care for their child during their time on a neonatal unit, it is also essential that the infrastructure exists to support parents to spend as much time with their baby as possible, including free overnight accommodation, a space to heat up or prepare simple meals and support with food and travel costs.

> "(We have) no family room, no facilities for siblings, no real waiting room and no transitional care. There is one parent-craft room but we would benefit from more. Mothers are discharged early from post-natal wards as well because of pressure on beds."
>
> (Consultant Paediatrician)

Psychological support

When a baby is born premature or sick, it is an extremely stressful and anxious time for parents. In most instances, parents will not know in advance that their child will require specialist care after birth and this shock can compound their feelings of stress and loss. It is therefore vital that there is adequate access to psychological support from admission to the neonatal unit, as well as after their baby has been discharged home.

> “No psychological support was available to us in either of the hospitals my babies were cared in, I subsequently have gone through a prolonged period of severe depression and anxiety for over three years, a big part of which I’ve been told is due to Post Traumatic Stress from four premature births.”
>
> (Mother of twins born at 31 weeks)

Evidence

Vigod et al. showed in their study that mothers of babies admitted to neonatal care were up to 40 per cent more likely to suffer from post-natal depression and other mental health conditions compared to the general population of new mothers.[47] Further to this Hynan et al. recommended in their 2015 study that the emotional needs of parents in the neonatal unit were of equal importance to the development of their babies and must have frequent input from experienced neonatal mental health professionals to support them throughout their stay.[48]

National standards: psychological support

The *Quality Framework* stipulates that a high quality service will have access to a range of allied health professionals, including a clinical psychologist.

The standards also state that in the event of a bereavement, a named consultant should make contact with parents to offer discussion and counselling. This should occur no more than seven weeks after a baby’s death.

Three out of 13 units, including one Level three unit, said they had no access to a clinical psychologist. While ten out of 13 units do have some access to this service, several units commented on the limited availability of this support. Even units with dedicated access to clinical psychology services highlighted that provision was inadequate. One noted that the current 1.7 WTE equivalent resource was shared with maternity services, meaning in reality the neonatal unit only received around 0.85WTE time, falling well short of the 3.1 WTE which would be required for a unit of their size.[49] Another noted that their 1 WTE clinical psychology team was shared across paediatrics, and another Level three unit stated that they could only refer to region-wide support.

Despite the clear requirement in the *Quality Framework* for parents whose child sadly dies to meet with a consultant within seven weeks and to be offered counselling, only four out of 13 services could offer parents access to counselling services, even via referral. This is a clear failing of NHS Boards and NHSScotland to ensure that MCNs and individual units have the resources to provide the support needed by parents who have lost a baby.

Despite the lack of access to these key professionals, it is welcome that 12 out of 13 units had access to a trained mental health professional of some kind, including a psychotherapist. However, these services were often patchy and poorly resourced and many units could only utilise these services by referring parents to a service outside of the unit. Two respondents commented that, while they could refer parents, direct access to these professionals in the neonatal unit would be beneficial. A further two units noted that their dedicated professional contact time needed to be increased in order to meet demand on the unit.

> “We met weekly with a psychologist who supported us throughout our son’s ten week hospital stay. This was something that the hospital organised automatically and was so helpful, we felt supported and it was great to be able to talk to someone outside of my family. Although we didn’t continue to see her once our son was discharged we were told how to make an appointment with her if we felt we needed it.”
>
> (Mother of baby born at 26 weeks)

Mental health is an area of priority for the Scottish Government and it is welcome that *Mental Health in Scotland – a Ten Year Vision* recognises the importance of perinatal mental health and the mental health of infants and children, by designating these as numbers one and two of their eight core priorities.[50] It is also welcome that the *Ten Year Vision* aims to target interventions towards mothers who are the most vulnerable and at risk. Bliss Scotland urges the Scottish Government to explicitly recognise that mothers whose baby is admitted to neonatal care are in this category due to the very high rates of poor mental health associated with this group.

It is essential that parents with a baby in neonatal care have access to good psychological support, available from admission and throughout their journey. Until this is available, the ambitions of the *Ten Year Vision* cannot be fully realised.

> “Given the range of antenatal problems and the complex nature of the babies in the unit with attendant high morbidity, more support should really be available to parents. Our current neonatal service includes many families from out of area who can access support while on unit but who cannot then access specialist perinatal input once repatriated to their referring hospital as perinatal input across the country is patchy. Increasing referrals from the maternity side of the service is currently putting pressure on existing support services to also meet neonatal need.”
>
> (Neonatal Consultant)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Conclusions and recommendations

Neonatal staff do an excellent job, but they are being put under considerable pressure as a result of inadequate resources available to services to meet national standards. Neonatal units across Scotland are unable to meet national standards across a range of areas, including staffing levels and accommodation for families.

We welcome the forthcoming focus on delivering improvements across maternity and neonatal care, with the publication of the Scottish Government's Review of Maternity and Neonatal Services, and its aim to provide the right care for every woman and baby every time. This provides a positive opportunity to address the significant challenges facing neonatal services now – in particular workforce and resourcing issues, as well as inadequate and inconsistent facilities for parents – while ensuring the service is fit for the future.

Recommendations

1 The Scottish Government and NHS Boards must recommit to all neonatal services meeting national standards for high quality care, and set out a timetable for this to happen.

2 The Scottish Government and NHS Boards must invest in neonatal care so that services can recruit the nurses, medical staff and other professionals they urgently need, and ensure that staffing gaps are addressed.

3 The Scottish Government and NHS Boards must commit to ensuring adequate funding for QIS and ANNP training is maintained, and work with MCNs and units to ensure staff can be released and that the resources are available to allow all staff to fulfil their training and development needs.

4 The Scottish Government and NHSScotland should create clear guidance outlining minimum standards on the level of free accommodation and other practical and financial support packages which should be available to enable family-centred care to be more easily embedded on neonatal units, with clear timescales and additional resources for implementation.

5 The Scottish Government and NHS Boards should invest in transitional care facilities and community outreach services so that babies and mothers can stay together where appropriate, and that babies can be discharged earlier, preventing the trauma of separation of mother and baby and reducing pressure on neonatal units.

Methodology

In June 2016, Bliss Scotland sent a survey to the 15 neonatal units that were operational during 2015/2016. A total of 13 units (87 per cent) responded.

The survey included questions about admissions, activity levels, staffing, training, facilities and parent support. Questions about admissions and activity level were for the financial year 2015/2016, though staffing questions related to a single day in March 2016 to get a snapshot of nurse and medical staffing. The survey also included space for comments, from which many of the quotes from health care professionals in this report are drawn.

Nursing requirements were calculated according to the nurse-to-baby ratios set out in the *Quality Framework* and took into account annual care days and occupancy rates for different categories of care at each unit.

In June 2015 Bliss Scotland surveyed ScotSTAR, the neonatal transport service, and their response is used in this report. Information they provided is also included in the UK-wide *Transfers of premature and sick babies* report published in April 2016. Further information was kindly provided by the transport service in 2016 which has also been included in this report.

Parents whose babies were cared for in neonatal units across Scotland also shared their stories with Bliss Scotland, and we have used their quotes in this report.

Glossary

Categories of care

- **Special care** is the least intensive level of neonatal care and is the most common. Babies receiving special care may need to have their breathing and heart rate monitored, be fed through a tube, supplied with extra oxygen or be treated for jaundice.

- **High dependency care** is provided to babies who need continuous monitoring, for example those who weigh less than 1,000g, or are receiving help with their breathing via continuous positive airway pressure or intravenous feeding, but who do not require intensive care.

- **Intensive care** is highly specialised care for the smallest and most seriously ill babies who require constant care and, often, mechanical ventilation to keep them alive.

- **Transitional care** is another type of care babies may receive in hospital. It allows babies who need some extra help, but do not need to be admitted to a neonatal unit, to stay with their mother with support from neonatal staff.

Medical tiers

- **Tier one** medical staff are junior staff members such as doctors new to the speciality and advanced neonatal nurse practitioners (ANNPs).

- **Tier two** medical staff are middle grade staff members such as speciality doctors and more experienced ANNPs.

- **Tier three** medical staff are medical consultants.

Managed Clinical Networks

There are currently three **Neonatal Managed Clinical Networks (MCN)** which are responsible for co-ordinating the care of babies in their areas across the range of neonatal units to ensure that babies receive the care that they need, as close to home as possible. When babies in the network need to be transferred, they will usually be moved to another unit within their MCN, but sometimes babies are cared for by other MCNs.

Neonatal units

- **Level one units** provide special care for their local population. Depending on local arrangements, they may also provide some high dependency care.

- **Level two units** provide special care and high dependency care and a restricted volume of intensive care (as agreed locally). Babies who require complex or longer-term intensive care will be expected to transfer to a Neonatal Intensive Care Unit.

- **Level three units** provide the whole range of medical (and sometimes surgical) neonatal care for the local population from a larger intensive care unit. Additional care will be provided for babies and their families referred from the neonatal network in which they are based. Admission of babies from other networks may occur to deal with peaks of demand or requests for specialist care not available elsewhere. Many will be sited within perinatal centres that are able to offer similarly complex obstetric care. These units will also require close working arrangements with all of the relevant paediatric sub-specialties.

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[2]Information Services Division (2015)
[3]For example, children born extremely prematurely are more likely than other children to have cerebral palsy, learning difficulties, behavioural problems and breathing difficulties. More information can be accessed at: epicure.ac.uk/overview/main-challenges
[4]Neonatal Data Analysis Unit (2013), NDAU 2013 Report, p.4
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“Although our ward was chronically understaffed, the staff who worked there were generally exceptional and made time to include my husband and myself in every aspect of our son’s care. We felt like an essential part of his team. I will never be able to thank them enough for what they did for our family.”

(Mother of baby born at 31 weeks)

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