# Bliss baby report 2016: time for change

## Wales

Bliss
for babies born premature or sick

# Contents


**Foreword** 3

**Summary of findings** 4

**Introduction** 7

**Nursing** 8

Shortfall in nurses 8

Specialist nurses 11

**Medical staffing** 14

Shortfall in medical staff 14

**Other health professionals** 17

**Occupancy levels** 19

**Avoidable admissions** 20

**Transfers** 22

**Support for families** 25

Accommodation and meals 25

Psychological support 27

**Conclusions and recommendations** 28

**Methodology** 30

**Glossary** 31

**References** 32


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# Foreword

Neonatal services provide vital specialist care to babies who are born premature or sick. The care that babies receive in the first few hours, days and weeks of their life determines their chances of survival and long-term quality of life.

There has been welcome progress in the development of neonatal services in Wales in recent years. This has included the publication of clear standards that provide a framework for the delivery of safe, effective, high quality care in 2008, and the successful establishment of the Wales Neonatal Network in 2010 and dedicated neonatal transport services in 2011. However, despite these developments, neonatal services continue to fall far short of standards that set out what is required to deliver safe, high quality care for babies born premature or sick.

Six years ago a committee of Welsh Assembly Members found considerable evidence of problems in the recruitment, retention and training of staff that were a major challenge for neonatal services. The Welsh Government accepted its recommendations for addressing these challenges and this represented an important opportunity to make progress. However, since the committee's report and the last *Bliss baby report* were published in 2010, these issues have not been resolved. Neonatal units are still understaffed and under resourced, and this puts babies at risk.

This report should be a wake-up call for policy makers. With a newly elected government in place, it should be a priority for decision makers to ensure neonatal units have the staff and the funding they need to deliver a safe, high quality service so that all babies born premature or sick in Wales have the best possible care.

Caroline Davey
Chief Executive

# Summary of findings

Evidence from neonatal units, neonatal transport services and parents across Wales shows worrying shortages of the nurses, doctors and other essential health professionals that premature and sick babies need. This puts neonatal units under severe pressure; it leaves them unable to meet national standards for quality and safety or support parents to be involved in their baby's care.

Parents have told us how much they appreciate the dedication and hard work of individual staff members who care for their babies, but these professionals are being pushed to the limit.

- Only two out of ten neonatal units had enough nurses to staff their cots in line with national standards
- Half of the nursing shortfall at neonatal units is due to insufficient funding
- Only two out of 11 neonatal units were funded to have enough nurses with a specialist qualification in neonatal care
- All neonatal units identified difficulties with at least one aspect of nurse training and development
- Over half of neonatal units did not have enough medical staff to meet minimum standards for safe, high quality care
- In South Wales there is no dedicated transport service to move babies at night
- Nearly a quarter of all emergency transfers took place due to a shortage of staffed cots rather than medical need, putting babies at unnecessary risk and adding to families' stress and worry
- None of Wales' neonatal intensive care units have enough overnight accommodation for parents to meet national standards, leaving many unable to stay close to their very sick baby
- Parents have no access to any psychological support at over half of units

Bliss is calling for urgent action from the Welsh Government and Health Boards to address these challenges and ensure that neonatal services have the funding and staff members they need to meet national standards. This is vital for services to provide safe, high quality care for vulnerable babies and give them the best possible chance of survival and quality of life.

# Neonatal services under pressure

## HOSPITAL

**8 out of 10 units** did not have enough nurses to staff all of their cots

**Over half of units**

did not have enough medical staff to meet standards

**9 out of 11 units** did not have enough nurses with a specialist qualification in neonatal care

**No NICUs**

had enough overnight accommodation for parents of critically ill babies

**Parents** had no access to psychological support at **over half of units**

**23%** of emergency transfers were because the unit was full

# Introduction

Over 2,700 babies are born in Wales each year who need specialist neonatal care to help them survive and thrive.[1 2] That means one in 12 of all babies born is admitted to neonatal care because they are premature or sick.[3]

Many of these babies will grow up with no ongoing health conditions, but some children will face a range of health complications in later life.[4] The care that these babies receive while in hospital is crucial for both their survival and their long-term quality of life. However, our findings show that many neonatal services in Wales do not have the staff and resources they need to provide safe, high quality care in line with national guidelines.

Premature and sick babies are currently cared for in 11 neonatal units across Wales.[5] Babies' care is co-ordinated by the Wales Neonatal Network which advises Health Boards and works with units and neonatal transport services to ensure that babies receive the care they need, as close to home as possible.

This report is based on information provided by all 11 neonatal units and two transport services in Wales. Parents in Wales also shared their stories with Bliss. Please see the methodology for more information about how this research was conducted.

**Why are babies admitted to neonatal units?**
49 per cent of babies admitted to neonatal care in Wales are born full term, but are sick.[6] For example, they may have an infection, difficulty breathing or a genetic condition.

51 per cent of admissions are babies who are born prematurely, at under 37 weeks' gestation. 9 per cent are very premature, born under 32 weeks' gestation. These babies are born before they are fully developed and often spend the longest time in neonatal care.

## Quality standards

The *All Wales Neonatal Standards* were first published by NHS Wales in 2008 and updated in 2013. These standards set clear guidelines for the planning and delivery of safe, high quality neonatal care. The British Association of Perinatal Medicine (BAPM) also published its *Service Standards for Hospitals Providing Neonatal Care* (3rd edition) in 2010 and *Optimal Arrangements for Neonatal Intensive Care Units in the UK* in 2014 which include requirements on the safe staffing of neonatal units.

# Nursing

Nurses provide the majority of care to premature and sick babies, and there is clear evidence that having enough experienced nurses to provide direct hands-on care has a big impact on babies' chances of survival and long-term health.[7 8 9 10 11 12 13] Therefore, it is vital that all neonatal units in Wales have enough nurses, with the right skills and competencies, to be able to meet national standards for safe care.

**National standards: nurse staffing levels**
Both the *All Wales Neonatal Standards* and BAPM's *Service Standards* set out the minimum number of nurses that are needed to safely care for babies in neonatal care: there should be one nurse for every baby in intensive care, one nurse for every two babies in high dependency care, and one nurse for every four babies in special care.

The Wales Neonatal Network calculates the number of nurses needed in Wales according to the number of commissioned cots at each unit.[14 15]

## Shortfall in nurses

Only two out of ten neonatal units[16] had enough nurses in post to be able to staff all of their commissioned cots in line with national standards, both of which were special care baby units. Having all of the available cots at a unit fully staffed enables services to cope with peaks in demand while still meeting the safe staffing standards.

Bliss calculates that 87 more nurses are needed at the eight units which did not have enough nurses in post to staff their commissioned cots in 2014/15. This reveals a worrying trend, as progress that was made in recent years in addressing the nursing shortfall in Wales has been reversed. In 2011, the Wales Neonatal Network calculated that 83 more nurses were needed in total for neonatal units to be able to staff their commissioned cots in line with national guidelines.[17] The following year, in 2012, the Network reported that this shortfall had been reduced to 42 nurses.[18] However, these gains have gradually been lost.[19]

None of the neonatal intensive care units in Wales even had enough nurses in post in 2014/15 to care for the babies that were actually admitted. They would have needed 24, 18 and 11 more nurses respectively to care for all of the babies they looked after in line with the nurse to baby ratios set out in the *All Wales Neonatal Standards*.[20] The actual number of nurses caring for babies at these units ranged from 64 to 79, so the shortfalls were proportionally very large. This shows that at the busiest and most specialist neonatal units in Wales safe staffing levels are not being met on a day-to-day basis.

Concerns about the impact on neonatal services of nurse staffing shortages have been raised over many years. In 2010, the National Assembly for Wales' Health, Wellbeing and Local Government Committee found that, "there was considerable evidence that problems in recruiting, retaining and training the staff required to deliver the service remain a major challenge."[21] These concerns were also identified by Bliss[22] and reiterated two years later in the Children and Young People Committee's *Inquiry into Neonatal Care*.[23] Despite these

warnings, national shortages have not been addressed and are still a barrier to neonatal units in Wales providing high quality care in line with NHS Wales' standards.

Recent research has shown that a decline in one-to-one nursing in intensive care is linked to a higher mortality rate for babies.[24] Nursing shortages are also associated with a higher risk of infection for babies in neonatal units.[25 26] Urgent action is needed to ensure the nursing shortages identified in this report do not continue to grow, putting vulnerable babies at risk.

> "Sometimes staffing was short. Often my son's alarms would be left unattended as nurses were too busy. On one occasion he turned blue after his alarms were ignored for 15 minutes – I had to run and get help…" (Mother of baby born at 25 weeks)
>
> "Our experience was a positive one; there was always a nurse with our little one and doctors were always in the unit." (Mother of twins born at 25 weeks)

### Funding

Neonatal units in Wales are often not allocated enough money to recruit the nurses they need to provide safe, high quality care to premature and sick babies. Of the eight neonatal units which did not have enough nurses in post to staff all of their funded cots in 2014/15, none of these would have enough nurses even if all of their vacancies were filled. These units would still be falling short by 45 nurses in total. This means that over half (52 per cent) of the nursing shortfall is due to inadequate funding.

Additional investment is needed so that all neonatal units in Wales can recruit at least the minimum number of nurses they need to meet national standards. This is vital for services to safely care for all of the babies they look after and give them the best possible chance of survival and quality of life.

**8 out of 10 units did not have enough nurses to staff all of their cots**

## Recruitment

An important factor driving the nursing shortfall at neonatal units in Wales is the difficulty they have recruiting nurses to fill vacancies. There were 47 unfilled nursing posts at the ten neonatal units which provided information about their nurse staffing.

In part, this is due to national skills shortages across the health and care systems. However, these shortages are particularly acute in neonatal care. The 2016 report of the Migration Advisory Committee on nursing shortages found that there is a UK-wide undersupply of nurses and a vacancy rate of 5.6 per cent in Wales.[27] However, our research shows that 9 per cent of funded neonatal nurse posts were unfilled, highlighting the particular difficulties within the Welsh neonatal service.

There are several reasons why neonatal units may find it difficult to recruit enough nurses. One factor is the availability of nurse training places in child health. For example, there are only 100 child branch places in Wales for nurses starting their training in September 2016.[28] This has declined since 2014, which is a worrying trend. Bliss calculates that 87 more nurses are needed to work in neonatal units alone, indicating a shortfall in nurse training places to meet future workforce requirements.

Another issue is that there are a limited number of placements on neonatal units available. Therefore, some students do not have exposure to neonatal care during their training, making them less likely to choose a career in neonatal nursing.

The Wales Neonatal Network also reports that many nurses are leaving in favour of work that has more family-friendly working hours, or to become advanced neonatal nurse practitioners; in a six month period in 2015, 20 experienced neonatal nurses left the neonatal nursing workforce.[29]

> "Ensuring units have the correct nursing establishment is vital for safe nursing practice, infection control and parents' wellbeing." (Lead Nurse)

## Specialist nurses

Babies' chances of survival and good long-term health do not just rely on having enough nurses. Evidence shows that it is also crucial that the smallest and sickest babies are cared for by nurses with the right education, skills and competencies to provide the specialist care they need.[30 31] Increasing the number of specialist neonatal nurses in intensive and high dependency care is associated with a 48 per cent decrease in babies' mortality,[32] so it is vital that services get this right.

**National standards: specialist nurses**

The *All Wales Neonatal Standards* and the BAPM *Service Standards* require that babies in intensive care and less stable babies in high dependency care should be looked after by a nurse who is Qualified in Speciality in neonatal care. More stable babies in high dependency and those in special care should be looked after by nurses who are under the direct supervision and responsibility of a specialist neonatal nurse.

The *Toolkit for High-Quality Neonatal Services*, published in 2009, states that a minimum of 70 per cent of the registered nursing and midwifery workforce establishment[33] should be Qualified in Speciality.[34] While this standard is only directly applicable in England, it is used by the Wales Neonatal Network to assess services in Wales.

However, only two of the neonatal units in Wales were able to meet the standard that at least 70 per cent of their establishment should be Qualified in Speciality. Both of these units were local neonatal units. This means that even neonatal intensive care units, the most specialist units, do not have enough nurses with proven competencies in providing specialised care for the smallest and sickest babies.

### Ongoing training and development

To address the severe shortage of specialist nurses at neonatal units in Wales, it is essential that nurses have access to appropriate postgraduate training and development to acquire the high level competencies that they need to care for very sick and vulnerable babies.

All 11 neonatal units in Wales had difficulty with at least one aspect of nurse training and development. The most common problem, reported by eight units, was difficulty releasing nurses from their frontline duties for training due to an inability to backfill these posts while they were away. For example, a senior nurse at a neonatal intensive care unit commented that training had been cancelled due to staff shortages, and a service manager at a special care baby unit said that they sometimes struggle to release staff while still maintaining minimum staffing levels.

Two units, one local neonatal unit and one special care baby unit, said that it can be a challenge for nurses to maintain competency levels and skills because they do not have enough clinical exposure to babies with complex care needs. One unit was also concerned about the time allowed for speciality training, suggesting that placements may not be long enough for staff to develop all of the skills they need.

No neonatal units in Wales reported problems with funding for nurses' ongoing training and development. This is very welcome, and it is essential that Health Boards continue to make this funding available, as ongoing investment in nurse training is vital in order to address the worrying shortage of specialist nurses that exist at nine out of eleven neonatal units in Wales.

"Once staff are Qualified in Speciality it is important that knowledge and skills are retained and updated regularly by exposure to intensive and high dependency care." (Lead Nurse)

"I found it very stressful not being able to talk to senior staff about my baby's care and health… and feeling like I was intruding on nurses' time when I wanted to ask them something. They were always very busy." (Mother of baby born at 24 weeks)

"Experienced neonatal nurses are leaving to become advanced neonatal nurse practitioners, resulting in gaps that are filled by newly qualified nurses not currently Qualified in Speciality." (Lead Nurse)

**9 out of 11 units did not have enough nurses with a specialist qualification in neonatal care**

# Medical staffing

Neonatal units must have the right mix of medical staff to safely manage babies' care. 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 advanced neonatal nurse practitioners, and seven tier three (expert) staff members who are medical consultants.

**Special care baby units:** medical staff may be on a shared rota with paediatrics, but at least one consultant should have a lead interest in neonatology. In some settings tiers one and two may be merged.

**Local neonatal units:** tier one staff should only cover the neonatal unit, though other staff members may be shared with general paediatrics. A minimum of one consultant should have a lead interest in neonatology and the other consultants covering the service must have expertise in neonatal care.

**Neonatal intensive care units:** all medical staff at all levels should have their clinical time devoted to neonatal care; there should be no crossover with general paediatrics. There may be extra resident consultants on the tier two rota but there must be 24/7 availability of a consultant neonatologist in addition to this.[35] The largest units will need many more; BAPM's *Optimal Arrangements for Neonatal Intensive Care Units* (2014) sets out the extra medical staff they need to take on.

## Shortfall in medical staff

Over half of neonatal units, including two out of three local neonatal units and four out of five special care baby units, did not have enough medical staff to meet minimum standards for safe, high quality care. This could underestimate the scale of the problem, as some units may need staff in addition to the minimum requirements, depending on the demands of the service.

Six units did not have enough tier three (expert) staff members and five of these units also did not have enough tier two (middle grade) staff members. One unit did not have enough tier one (junior) staff on its medical rota.

This means that half of the neonatal units in Wales do not have the expert and middle grade medical staff they need to be able to meet minimum standards for quality and safety. These shortages are at more than one level of seniority which could make it especially difficult for units to cope and to provide a safe level of care.

Local neonatal units should have tier one (junior) staff whose time is dedicated to the neonatal unit, ensuring that they can focus on babies in neonatal care rather than dividing their attention with other paediatric patients. However, only one local neonatal unit had a tier one rota that was fully dedicated to neonatal care. One local neonatal unit had a partially dedicated tier one rota, but staff shared their time with general paediatric care during nights and weekends. The tier one staff at another local neonatal unit did not have any of their time dedicated to the neonatal service at all.

"There is huge pressure as there are gaps in the tier two rota. The posts are not filled by the Deanery and there are not enough non-training doctors around." (Senior Nurse)

"The shortage of junior doctors (trainees and specialty doctors – we have a shortage of both!) is a great concern." (Consultant Neonatologist)

## Funding

An important factor causing the shortfalls in medical staff is that neonatal units in Wales are often not funded to recruit the doctors and advanced neonatal nurse practitioners that they need. Even if all medical vacancies were filled at the six units unable to meet minimum standards on medical staffing levels, four units would still not have had enough medical staff in place during 2014/15 to meet minimum standards for safe, high quality care.

## Recruitment

Another substantial barrier to achieving the right staffing levels is that neonatal units in Wales struggle to recruit the medical staff they need to provide a safe level of care. Eight out of 11 units reported at least one unfilled medical vacancy, with tier one (junior) and tier two (middle grade) medical posts particularly difficult to fill.

The 2014/15 Royal College of Paediatrics and Child Health (RCPCH) workforce survey also found that there were a very high number of vacancies in neonatal and paediatric inpatient services in Wales, at 28 per cent for tier two (middle grade) rotas.[36] Wales also had a comparatively low rate of locum cover, with only 16 per cent of vacancies being filled by locums.[37] This suggests that it is very difficult for many Welsh units to cope with rota gaps by finding locums to take on shifts, leaving them short staffed on a day-to-day basis.

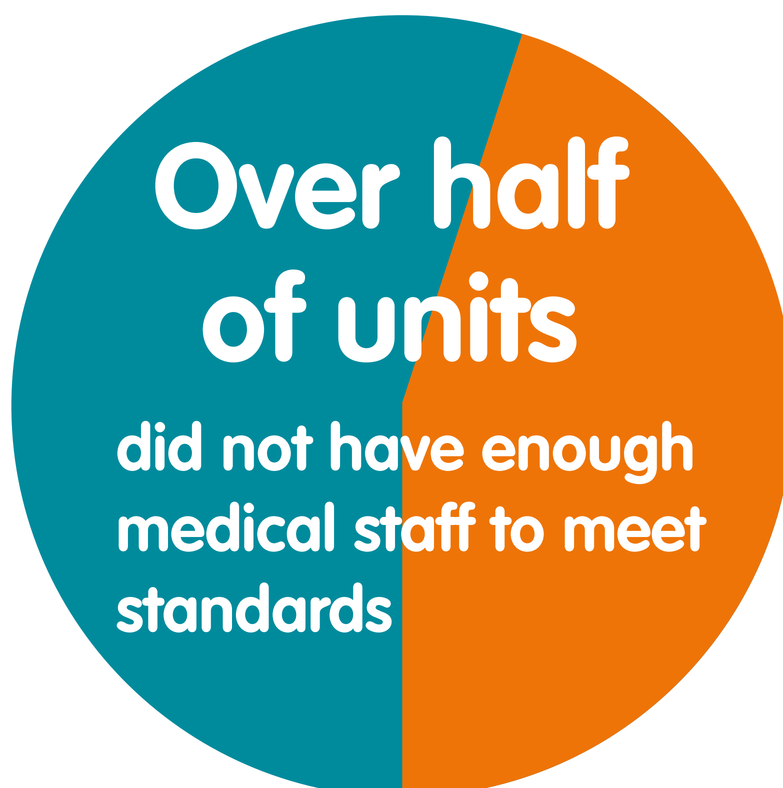
There are many possible reasons for these shortages. For example, there are a limited number of medical training places available due to long-term workforce planning considerations about the number of consultants that will be needed in the future. This issue will become more acute in September 2016, as one of the three neonatal intensive care units in Wales will no longer be a training centre. This means that it will have to fill its medical rota entirely without medical trainees.

Another factor is that paediatric medicine, which includes neonatal medicine, has high numbers of international medical graduates so visa restrictions on international workers may be having an impact on medical recruitment in neonatal care.[38]

Finally, nurse staffing shortages and barriers to training also make it difficult for units to fill medical rota gaps with advanced neonatal nurse practitioners.

This combination of factors has left many neonatal units struggling to meet minimum requirements for medical staffing. This is an urgent problem and a long-term challenge for many neonatal units and the babies they look after. In recent years, Health Boards across Wales have undertaken reviews of neonatal care and other hospital services with a view to making the staffing of services more sustainable. It is vital that the Welsh Government and Health Boards now commit to making sure that all units are appropriately staffed to meet national standards and ensure the safe care of babies. This will require investment and a commitment to ongoing collaborative workforce planning.

> "There are insufficient doctors on the training scheme to fill the posts, and that is across specialties, including neonates. It is even harder to fill the non-training posts. Most of these are with doctors from outside of the UK." (Consultant Neonatologist)



# Other health professionals

As well as doctors and nurses, babies need access to a wide range of other professionals with expertise that can help them to survive and have the best possible quality of life. Many allied health professionals and other experts can make a huge difference to babies' development, help parents to understand their babies' needs and support other staff.

**National standards: allied health professionals and other specialists**

The *All Wales Neonatal Standards* and the BAPM *Service Standards* outline the range of professionals with specialist knowledge and skills who babies need to be supported by. These include physiotherapists, occupational therapists and neonatal speech and language therapists, all of whom play a very important role in supporting families, promoting babies' neurodevelopment, reducing pain, improving communication and supporting feeding. All units should have a designated nurse with responsibility for breastfeeding, and babies should have access to a dietitian and a pharmacist who should both have specialist knowledge of neonatal care.

There is inconsistent access to these professionals at neonatal units across Wales. Five out of 11 units in Wales, including two out of three neonatal intensive care units, had no access to an occupational therapist, even via referral to another service. Three units had no access to a speech and language therapist and three had no access to a specialist radiographer. Worryingly, one neonatal intensive care unit had no access to an occupational therapist, speech and language therapist or a neonatal pharmacist, even via referral to another service.

Even fewer units had professionals with dedicated time in their work plan to spend with babies, families and staff on the unit each week. There are important advantages to working regularly on a neonatal unit, as professionals can integrate into the neonatal team, influence the way that the team works, and get to know families.

If babies do not receive support from the full range of neonatal professionals when they need it, this can have an impact on the quality and safety of their care and on their long-term health and development. For example, poor nutrition or pain management may affect babies' neurodevelopment as they get older.[39 40 41] A multidisciplinary assessment prior to discharge can also support families to overcome issues such as feeding difficulties which can reduce babies' care needs and prevent hospital admissions later on. Investing in the right treatment and therapies for babies can affect how much support they need from the health and social care system when they grow up, so it is important for individual babies, families and the public finances that NHS Wales gets this right early on.

"Our baby was seen by a speech and language therapist while in special care. He had difficulties in feeding, so the therapist helped us by using techniques which made feeding much easier for him and less stressful for us all." (Mother of twins born at 25 weeks)

"We saw a dietitian but only after I insisted to a doctor that we needed to see one, as I was very concerned. My concerns were right and we are continuing to see a dietitian nearly four years later. It was very hard to get the doctor to listen to me." (Mother of twins born at 29 weeks)

# Occupancy levels

Evidence shows that having a high occupancy of cots on neonatal units has a negative impact on babies' survival rates. For example, research has found that babies cared for by neonatal intensive care units at 50 per cent occupancy had about 55 per cent lower risk of dying than babies admitted to units with full occupancy.[42]

### National standards: occupancy

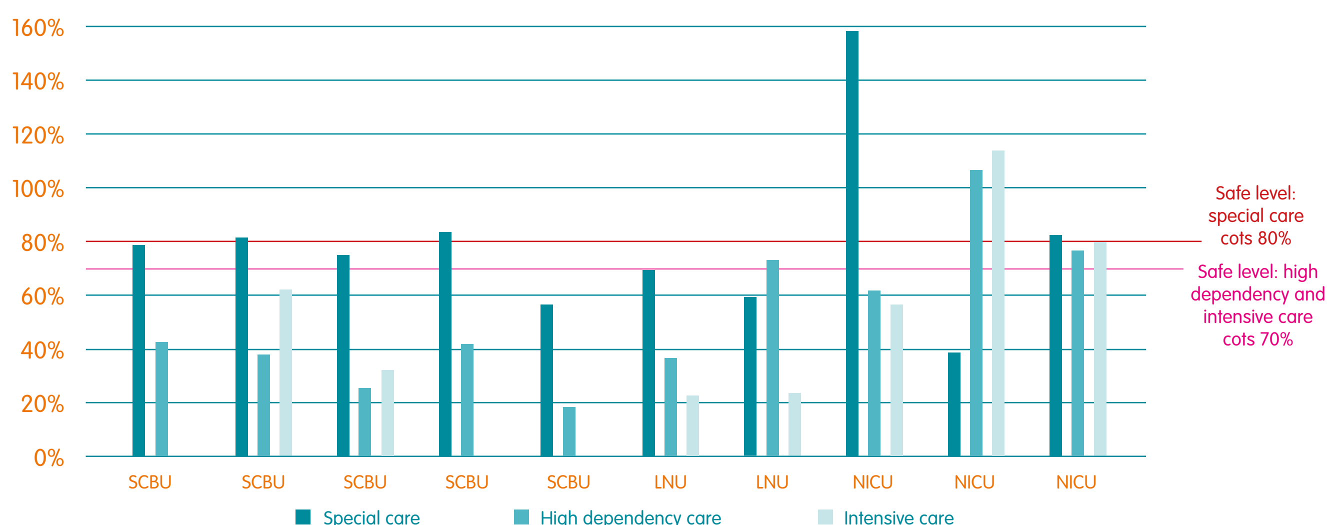
The Wales Neonatal Network advises that cots in special care should not exceed 80 per cent occupancy on average, while cots in high dependency and intensive care should not exceed 70 per cent occupancy on average. In addition, neonatal units should not exceed 70 per cent occupancy in total. This means that units should not consistently have babies in more than seven out of ten cots in order to meet safety standards.

Conversely, if neonatal units have low average occupancy rates then this can mean that care is not being organised in the most efficient way.[43] However, in some situations and some parts of the country, for example where units are quite spread out already, services with low occupancy levels could be needed to prevent babies and families from having to travel very long distances from home.

Occupancy levels at neonatal units in Wales varied widely, from 49 per cent on average at one special care baby unit, to 88 per cent at a neonatal intensive care unit. Average occupancy levels at half of all units, including all neonatal intensive care units, exceeded the Wales Neonatal Network standard that units should not have more than 70 per cent of their cots occupied in total.

All special care baby units had very low occupancy of their high dependency cots, ranging from 19 per cent to 45 per cent occupancy on average. This could indicate that there are some problems with the distribution of resources across Wales which need to be addressed to ensure that all neonatal units have the right number and mix of staffed cots to meet the needs of the babies they look after.

**Average occupancy of neonatal units in 2014/15 by category of care**




Ten out of 11 units in Wales responded with information about the care they provided.
The intensive care cots at two special care baby units were intended for short term stabilisation rather than ongoing care.
In addition to the care provided that is represented in the graph, the three special care baby units that did not report having commissioned intensive care cots did provide 46, 102 and 21 intensive care days respectively.

# Avoidable admissions

One of the pressures on neonatal services is the admission of babies to neonatal units who could be more appropriately cared for in other settings. There is wide variation in the number of babies admitted to neonatal care in Wales 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.

At the four neonatal units which provided information about their full term admissions, the proportion of all babies admitted who were full term without congenital malformations ranged from 39 per cent at one special care baby unit to 60 per cent at a local neonatal unit. This reflects findings by the Wales Neonatal Network that the proportion of full term babies born in maternity units who were admitted to the neonatal unit ranged from three per cent to ten per cent.[44]

Unnecessary admissions put extra pressure on neonatal units, are stressful and traumatic for families, and have a negative impact on babies. When babies can stay with their mothers in transitional care, where their mother can look after them with help from staff, they are more likely to benefit from breastfeeding and family-centred care (see p.25). As a result, appropriate transitional care can reduce the length of babies' hospital stays.[45]

The Wales Neonatal Network has made it a priority to support the development of transitional care arrangements and to investigate whether there are other methods that might help to reduce full term admissions to neonatal units.[46] Health Boards and the Welsh Government should support the development of transitional care facilities and undertake a review of full term admission rates and the underlying causes of variation in Wales.

# Transfers

Neonatal transfers are an integral part of neonatal care, allowing babies to be cared for in the right level of unit, as close to home as possible. There are two neonatal transport services in Wales which undertook 588 transfers of babies between hospitals in 2014/15. In North Wales, the transport service also works with the Cheshire and Merseyside Neonatal Transport Service which provides some transfers.

**National standards: neonatal transport**
The *All Wales Neonatal Standards* state that there should be a 24-hour a day transport service, staffed by trained personnel, which can provide rapid and timely transport of babies to and from neonatal units within Wales and across country boundaries. For more information about neonatal transport, see Bliss' report, *Transfers of premature and sick babies.*

There has been significant progress in recent years which has included the establishment of dedicated 12-hour neonatal transport services in 2011, and the recent changes to the North Wales service which now operates 24 hours a day, seven days a week.[47] However, in South Wales the transport service is only funded from 8am to 8pm, leaving neonatal units reliant on neighbouring transport services or neonatal unit staff when babies need to be transferred urgently during the night.[48]

It is important that commissioners and Health Boards take urgent action to address variation between North and South Wales and make sure both transport services have the funding and resources they need to provide a full-time service to all babies who need it, in line with the *All Wales Neonatal Standards*.

"When I was admitted I was told that the unit only had one space and I needed two, so I would have to be moved to Cardiff or Bristol. I was devastated as I'd experienced my local neonatal intensive care unit in my previous pregnancy and didn't want to go anywhere else… Plus I have a six year old so I didn't know how I was going to manage being so far away." (Mother of twins born at 24 weeks)

"Babies in South Wales have to rely on fragile and ad hoc services during the night because the transport service is only available 12 hours a day."
(Consultant Neonatologist)

While the majority of neonatal transfers are necessary so that babies can receive care in the right level of unit, as close to home as possible, transfers also take place for non-clinical reasons. There were 66 transfers of babies in 2014/15 due to lack of capacity at the transferring neonatal unit; that's a worrying 23 per cent of all emergency transfers.[49] This shows that neonatal units are under pressure and is one way they are coping with being understaffed and over capacity, however it puts babies at risk.[50 51]

When babies are moved due to lack of capacity rather than clinical reasons, 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 who they have got to know.

**23%** **of emergency transfers were because the unit was full**

# Support for families

Family-centred care places parents at the heart of their baby's care, empowering them to take the lead in caring for their baby through feeding, bathing and comforting. It can lower a baby's stress level, promote better health, shorten hospital stays and reduce hospital readmissions.[52 53] It helps parents to bond with their baby, resulting in better long-term outcomes for the whole family.[54]

Regularly needing to leave the hospital to go home to sleep or to buy an affordable meal creates a barrier to parents being fully involved in their baby's care. Parents often face huge financial costs as a result of having a baby in neonatal care and may not be able to afford a hotel, travel costs and expensive meals, especially if their baby is in hospital for several months.[55] Therefore it is essential that all neonatal units have accommodation for parents, basic kitchen facilities and support with meal and travel costs so that practical concerns do not get in the way of parents being with their baby.

**National standards: family-centred care**
The *All Wales Neonatal Standards* recognise the importance of family-centred care, setting out the minimum dedicated facilities that neonatal units should have in place for parents. For example, there should be one room per intensive care cot for parents. The room should be free of charge, have bathroom facilities, and be within a ten to 15 minute walk of the unit. There should be an additional two 'rooming in' rooms within or next to the unit for parents to stay in with their baby before going home. Units should also have a parent sitting room, a play area for siblings, and access to hot drinks and food.

## Accommodation and meals

All of the neonatal units in Wales said they had some overnight accommodation at the hospital to enable parents to stay close to their baby, though at several units this was very limited. None of the three neonatal intensive care units had enough parent accommodation to meet the *All Wales Neonatal Standards* requirement for one room per intensive care cot. Of the three local neonatal units in Wales that had intensive care cots in regular use, only two had sufficient parent accommodation to meet these standards. This means that many parents, including parents of the sickest and most fragile babies, cannot stay at the hospital and instead have to travel home every night or pay for accommodation close by.

Some special care baby units in Wales regularly admit babies who come from a very wide geographical area, so it is important that they are able to accommodate parents who have to travel a long way to be with their baby even if the unit does not have intensive care cots. NHS Wales should update the *All Wales Neonatal Standards* to reflect this.

Access to kitchen facilities and free meals was very variable and at some hospitals restrictive criteria meant that only breastfeeding mothers benefited from free meals. Many mothers of premature babies are unable to breastfeed or do not want to, so it can be upsetting to be denied support for this reason. Both neonatal intensive care units which responded to the survey question had this restrictive criteria in place, and neither of these units had food preparation facilities. This means that parents of the smallest and sickest babies often have to worry about where they are going to eat and how much it will cost, as well as spending time away from their baby.

Promoting family-centred care has proven benefits for babies, and supporting parents to provide appropriate care themselves can help to ease the pressure on busy neonatal unit staff. Health Boards should take this into account when they are considering building, adapting or acquiring new facilities as it is in the interests of babies, families and staff to ensure that units can meet national standards for supporting parents. They must also take immediate action to support parents' direct involvement in their babies' care until it is possible to improve on-site facilities. For example, this could involve helping parents to access a paid-for local bed and breakfast and providing subsidised meals in the hospital.

"My only issue is that more should be done to provide parents with accommodation in hospitals as it's the hardest thing in the world to do, leaving your sick baby every night. Even though they are in the best of places and have the highest quality of care it's not right being kept away from your baby that you can barely even touch." (Mother of baby born at 24 weeks)

"There is only limited accommodation available so it is allocated on a priority basis." (Senior Nurse)

"There should be a discount for the canteen. Taking a coffee break or having lunch, plus parking and daily fuel added up and put extra stress on me at a difficult time." (Mother of baby born at 32 weeks)

**No NICUs**

**had enough overnight accommodation for parents of critically ill babies**

## Psychological support

Having a premature or sick baby who needs specialist care to help them survive is a difficult experience for all parents, and many need emotional support to help them cope and bond with their baby. They are also more likely than other parents to suffer from mental health problems as a result of their experience, with up to 40 per cent of mothers of premature babies affected by postnatal depression.[56] The professionals who look after very small and sick babies also need support to do their jobs well in a stressful environment.

**National standards: psychological support**

The *All Wales Neonatal Standards* state that families should have access to support services which include a social worker, bereavement counsellor, psychiatric support and psychological advice by trained clinical psychologists specialising in neonatal care. The BAPM *Service Standards* are also clear that at neonatal intensive care units parents should have access to a trained counsellor without delay from the time their baby is admitted, and there should be ongoing support during the parents' time on the neonatal unit.

Only five out of 11 neonatal units in Wales were able to offer parents access to psychological support of any kind, either on the unit or via referral to another service.

None of the three neonatal intensive care units had a dedicated trained mental health worker[57] available to parents without delay, as required by the BAPM *Service Standards*. Parents at two neonatal intensive care units were not able to access this support at all, even via referral to another service outside of the neonatal unit. This means that parents with the most critically ill babies in Wales, and the staff members who look after these babies, are often left without the help and support they need.

"[Psychological support] is desperately needed but not available." (Ward Manager)

"No psychological support was offered. The nurses provided me with support on emotional days but it was quite a lonely experience, day after day of sitting next to an incubator for hours on end." (Mother of baby born at 32 weeks)

"There definitely needs to be a counselling service for parents. Having a premature baby is traumatic, especially when they have health issues or when there is a death. The nurses on the unit were fantastic and talked to me a lot about what was happening. They supported me through my daughter's palliative care and helped with funeral arrangements. However, having spoken to other parents we all agree that we needed some counselling." (Mother of twins born at 24 weeks)

# Conclusions and recommendations

Shortages of nurses, doctors and a range of other professionals are leaving many neonatal units in Wales struggling to meet minimum standards for quality and safety. Health professionals working in neonatal care do an incredible job and provide vulnerable babies with excellent care. However, when they are stretched too thin this puts babies at risk and leaves families without the support they need.

## Implementation of national standards

Shortfalls of nurses, doctors, psychologists and other specialists compound each other. When services are unable to meet national standards across several measures, this puts more pressure on existing unit staff and compromises the safety and quality of babies' care. Urgent action is needed from the Welsh Government and Health Boards to address the problems identified in this report before they become more entrenched.

### Recommendation

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

## Funding

Not all neonatal units in Wales have the funding to recruit enough staff members to meet minimum standards for quality and safety, and the neonatal transport service in South Wales is not resourced to transfer babies at night. Sufficient funding is needed urgently so that all neonatal services in Wales can provide a high quality service in line with national guidelines.

### Recommendations

2 The Welsh Government and Health Boards should invest in neonatal care so that services can recruit the nurses, medical staff and other essential professionals they urgently need.

3 Commissioners and Health Boards must ensure that transport services in both North and South Wales have the funding and resources they need to provide a full-time service to all babies who need it.

## Workforce challenges

Widespread problems with recruitment and training have been identified by this report and a range of other organisations. Concerns about the impact of skills shortages on neonatal services have been raised for many years; in its 2010 report, the Health, Wellbeing and Local Government Committee expressed concerns about the lack of specialist staff providing neonatal care and problems with recruiting neonatal doctors and nurses. These issues have not been addressed and it is now a matter of urgency that short and long-term solutions are found.

### Recommendations

4 Government and Health Boards, in consultation with the relevant Royal Colleges, should put medium to long-term plans in place which address the medical and nursing skills shortages and training issues identified in this report.

5 Health Boards, with advice from the Wales Neonatal Network, should look at how to ensure there are enough well qualified, experienced allied health professionals and neonatal pharmacists working across neonatal care so that all babies have the best possible chance of survival and quality of life.

## Support for families

Family-centred care benefits babies, families and staff. It can improve babies' outcomes, shorten hospital stays, help families to bond and reduce pressure on staff. Parents need support to be involved in their babies' care, including accommodation, facilities and psychological support to help them cope.

### Recommendations

6 Neonatal units in Wales should engage, or continue to progress, with the Bliss Baby Charter audit tool to assess the quality of family-centred care they provide and identify areas for improvement.[58]

7 Health Boards should ensure that all parents of babies in neonatal care are offered free accommodation, facilities for making drinks and preparing simple meals, and meal vouchers or free hospital meals.

8 NHS Wales should update the *All Wales Neonatal Standards* to recognise that accommodation is often needed by parents who have to travel a long way to be with their baby, even if their baby does not require intensive care or the unit does not have intensive care cots.

9 Health Boards, with advice from the Wales Neonatal Network, should look at how to ensure there are enough psychologists, counsellors and other mental health workers across neonatal care so that all parents and staff have access to psychological support in line with national standards.

## Maternity and transitional care

Unnecessary admissions to neonatal care put pressure on neonatal units, are traumatic for families, and have a negative impact on babies who are less likely to benefit from breastfeeding and family-centred care. The wide variation in full term admission rates across Wales must be better understood and addressed.

### Recommendations

10 Health Boards should invest in transitional care facilities so that babies and mothers can stay together when appropriate, reducing pressure on neonatal units and preventing the trauma of families being separated where this is avoidable.

11 Health Boards should undertake a review of full term admission rates and the underlying causes of variation in Wales.

# Methodology

In November 2015, Bliss sent a survey to the 11 neonatal units in Wales. All of these units responded.

Our unit survey included questions about admissions, activity levels, cots, staffing, training, facilities and parent support. Questions about admissions and activity levels were for the financial year 2014/15, though staffing questions related to a single day in March to get a snapshot of nurse and medical staffing across Wales. The survey also included space for comments, from which many of the quotes from health professionals in this report are drawn.

Nurse staffing levels were calculated according to the nurse-to-baby ratios set out in the *All Wales Neonatal Standards* and BAPM's *Service Standards*. We used the Neonatal Network Managers' Groups' method for calculating nurse staffing requirements and applied this to the commissioned cots at each unit, in line with the Wales Neonatal Network's approach.

In June 2015, Bliss surveyed the two neonatal transport services in Wales and both of them responded. Information they provided is included in this report and in *Transfers of premature and sick babie*s, published in April 2016.

Parents in Wales also shared their stories with Bliss online in July 2015 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.

**Commissioned cots** are cots that are available to use and that neonatal units are funded to provide.

### 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 advanced neonatal units practitioners.

- Tier three medical staff are medical consultants.

### Neonatal units

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

- Local neonatal units provide all categories of neonatal care, but babies who require complex or longer term intensive care are transferred to a neonatal intensive care unit.

- Neonatal intensive care units provide the whole range of neonatal care for their local population and the most specialist care for the smallest and sickest babies across their network. They are often co-located with other specialist services such as paediatric surgery.

**The Wales Neonatal Network** is responsible for co-ordinating the care of babies in its area 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 Wales, though some babies are cared for at units in England.

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[16]Ten out of 11 units provided information about the nurses they have in post; however two of these units (within the same Health Board) combined their nurse staffing data
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[58]More information available at: bliss.org.uk/baby-charter-audit-tool

**"As difficult as our time on the neonatal unit was, looking back we had the best care, support and advice from all the staff and we felt like we were part of a family. The staff were always very welcoming, helpful and supportive."**

(Mother of baby born at 24 weeks)

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