

Too little, too late?



Are we ensuring the best start
for babies born too soon?

The BLISS Baby Report 2007





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Foreword

It is my pleasure to introduce BLISS's third annual Baby Report. As with previous Baby Reports, we highlight where babies born prematurely or sick and their families are not receiving the quality of care they deserve. However, this report also aims to acknowledge where progress is being made around the country.

This year approximately 80,000 babies will require treatment in specialised neonatal baby units. BLISS, the premature baby charity, works closely with nurses, doctors and other healthcare professionals to improve the long-term outcomes for babies born too soon, too small or too sick. These highly skilled professionals deliver crucial support to the most vulnerable members of our society when they most need it.

In 2005 BLISS highlighted the fundamental injustice that newborn babies requiring intensive care face in the UK: that the one-to-one nursing that adults and children receive in intensive care is denied to babies. In 2007 we are sad to report that compliance with nursing standards for babies is actually getting worse.

The care of premature and sick babies is a rapidly developing field with new advances being made all the time. Survival rates and outcomes for premature babies continue to improve. However, this report clearly identifies that neonatal units are increasingly being forced to work well above their recommended capacity and with too few nursing staff. The service is close to breaking point and unless significant action is taken now the UK's babies and their families face a bleak future.

The time has come for the inequity of care for our babies to cease. Neonatal units desperately need the funding and resources to be able to invest in the appropriate levels of expert care, both now and for the future.

Some babies need a little extra help at the start of their lives. They deserve better.

Andy Cole
Chief Executive

Executive summary

In early 2007 BLISS sent a survey to every neonatal unit in the UK. The results revealed a service that is stretched to breaking point. Ten per cent of neonatal units were forced to refuse new admissions for an average total of eight weeks or more in a six-month period.

From 2005 to 2006, nursing numbers increased by two per cent while the number of days of care they provided increased by over five per cent. Demand is outstripping supply. Not only has compliance with minimum nursing levels got worse, but the increasing demand means that there is now even further to go to reach the required level.

Should the increase in nurses continue at the current rate and the demand for neonatal care remain the same, it will take 16 years to reach the number of nurses needed to comply with minimum standards at today's levels.

The scale of the problem is underestimated because nurses and doctors work beyond agreed capacity. Professionals faced with too many babies and too few staff often feel that it is their duty to try to cope with the situation rather than highlighting the shortage and refusing to take on more work. This has knock on effects on the standard of care they are able to provide and the amount of time they can spend with parents. It also has an impact on their ability to keep their skills and knowledge up to date in this rapidly evolving field of medicine.

The introduction of Payment by Results for neonatal care may help to improve the situation. It is essential, however, that a specific 'neonatal tariff' be set to endorse the standards set by the British Association of Perinatal Medicine.

The lack of dedicated neonatal transport is one of the key contributing factors to units being forced to work above their capacity and many transfers of premature and sick babies are still carried out on an ad hoc basis.

The introduction of neonatal networks in England has made improvements in training, transport, patient flow and sharing of good practice. However, this progress is being undermined by uncertainty over funding. This has resulted in managerial posts remaining vacant and instability in the structure of networks.

The emotional, physical and financial impact on parents of having a premature baby cannot be underestimated. Our survey revealed that many parents have to travel considerable distances at great personal expense to visit their child. Furthermore, 35 per cent of parents of twins reported that their children received treatment in separate hospitals.

Urgent action is needed to address this situation that has been allowed to continue for too long.





Introduction

The arrival of a new baby is supposed to be a joyous event to be remembered with happiness. It is hard for most of us to imagine the pain, shock and fear that new parents feel when their baby is born prematurely or in desperate need of medical help just to stay alive. Yet this is the case in the delivery of one in every eight babies born in the UK every year. The care that these vulnerable babies receive in their first hours, days and weeks can have an effect on their health, development and wellbeing for the rest of their lives.

BLISS was set up over twenty-seven years ago by a group of parents who had gone through the experience of having babies born prematurely or sick. They felt that there was inadequate funding of equipment such as incubators. BLISS was originally established therefore to raise funds for new life support equipment for neonatal units.

The BLISS parents also realised that there was very little information or support available to families during this traumatic and unexpected experience. So they began to establish a mutual support network to provide a helping hand and a sympathetic ear to other families going through a similar experience. We continue this work today with a helpline, website, online message board, a shared experience register and a range of leaflets and publications for families of babies born too soon, too small or too sick to cope on their own. BLISS also encourages and funds clinical research projects to make sure that innovative developments are supported in the vitally important field of neonatology.

Formal standards that set out the best model for providing critical care to children and adults are widely implemented. Whilst one to one nursing is provided for adults and children in intensive care, this is not the case for babies and the relevant standards have never been implemented.

In addition to our family support and research work, BLISS also campaigns for hospitals to be given the proper resources, management and funding to provide the best possible level of care.

BLISS strongly supports the work of neonatal nurses, doctors and other health professionals. They do a fantastic job in providing the care that premature and sick babies desperately need. It is crucial that these professionals are given the support, facilities and working conditions they need to be able to continue this vital work.



Purpose of this report

This report looks at the provision of services for these babies and their families across the UK. We look in detail at the care and services that neonatal units provide, how these units are organised, and how babies are transported from one place to another. We collected this information by conducting a Freedom of Information survey of all the neonatal units in the country (see Methodology, page 33). The chapters on neonatal networks and transport have been informed by a review of literature and reports supplied by neonatal health professionals. Finally, we look at what parents told us in a BLISS online survey about the care their babies received and the impact that the experience has had upon their lives.

Definitions

Birthweight	
Average birthweight:	3,400g / 7lbs, 8oz
Low birthweight:	2,500g / 5lbs, 8oz or less
Very low birthweight:	1,500g / 3lbs, 5oz or less
Extremely low birthweight:	1,000g / 2lbs, 3oz or less

Gestation	
Average gestation:	37 to 42 weeks
Premature baby:	Born before 37 weeks
Moderately premature:	Born between 35 and 37 weeks
Very premature:	Born between 29 and 34 weeks
Extremely premature:	Born before 29 weeks



Neonatal care

Babies who are born too soon, too small or too sick to cope on their own need to be cared for on specialist neonatal units. These babies are often extremely unstable and can develop serious complications, sometimes in a matter of minutes. Neonatology has made great advances in recent years. To cater for the complex needs of premature and sick babies, neonatal care is now provided in three levels. These levels, devised by the British Association of Perinatal Medicine (BAPM), are designed to ensure that the appropriate level of care is provided in a properly equipped and staffed environment.¹

Baby Edward, for example, was born at 24 weeks (16 weeks premature) in a level 3 neonatal Intensive Care unit. Before his birth his mother had had to be transferred while in labour because of a lack of suitable cots at her local

Special Care (Level 1)

This is the least intensive level of neonatal care. Babies who need Special Care need continuous monitoring of breathing or heart rate. They may need additional oxygen, tube feeding, antibiotics or light therapy for jaundice. This is also where babies who are recovering from more specialist treatment come to convalesce and recover. In Special Care, babies are usually treated in open cots and can be lifted out by their parents with help from nurses. There are more Special Care baby cots than any other type of neonatal cot because demand for this level of care is the greatest. Special Care may also be provided alongside the mother's maternity bed. This is called Transitional Care.

High Dependency Care (Level 2)

These units are for babies who weigh less than 1,000g (2lbs, 3oz), are receiving continuous positive airway pressure (CPAP) or intravenous feeding but who do not fulfil any of the categories for Intensive Care (see below). High Dependency units can provide Intensive Care, but only in the short term. High Dependency cots are usually closed incubators with complex monitoring equipment. With help from nurses, however, babies may still be lifted out to be held by their parents.

Intensive Care (Level 3)

Intensive Care is what the most critically ill babies receive. These babies need constant care just to keep them alive. Their organs may not yet be developed enough to allow them to survive without support. A level 3 unit is capable of providing the whole range of neonatal care – Special Care, High Dependency Care and Intensive Care – and some will also have specialist facilities such as neonatal surgery. The cots used in Intensive Care are highly specialised open or closed incubators that monitor the baby's vital signs and are fully integrated with the unit's life support system. As with High Dependency Care, nurses can lift a baby out of their cot so that their parents can hold them. This can be a complex procedure, however, because of the various tubes and wires that need to remain attached.



¹ *Standards for hospitals providing neonatal intensive and high dependency care (Second edition)*, British Association of Perinatal Medicine (BAPM), December 2001
http://www.bapm.org/documents/publications/hosp_standards.pdf



hospital. Edward received 12 hours of ventilation as soon as he was born. His breathing was then assisted for the next eight weeks by continuous positive airway pressure (CPAP). Edward also received treatment for a number of infections.

The medical staff then decided that Edward was well enough to be transferred to the level 2 High Dependency unit at his parents' local hospital where he spent a further four weeks on CPAP. Once his lungs had grown stronger Edward was moved from the High Dependency cot to a Special Care cot within the same neonatal unit just across the corridor. Here he spent another five weeks with oxygen being provided to him through a tube in his nostrils before finally going home.²

These different levels of care and the transfer of babies between them are made possible by arranging units in clinically managed networks. They ensure that the correct level of care is provided at the right time in properly equipped and staffed units. We will discuss neonatal networks further in the next chapter.

BLISS conducted a survey of the UK's neonatal units using the Freedom of Information Act 2000. We asked a series of questions covering such areas as admissions, numbers of cots, staffing and occupancy levels.

Key findings

- Stretched to breaking point – one in eight level 3 units that responded said that they operated at an average occupancy of 100 per cent or more for a whole year.
- Fifty-five per cent of level 3 units that responded are operating at or below 50 per cent of recommended minimum nursing levels.
- Although the overall number of nurses has increased, 45 hospitals have cut the number of neonatal nursing posts (whole time equivalent).³
- Only 12 units across the UK claim to operate at or above the recommended minimum nursing levels.
- Compliance with minimum nursing levels is getting worse.
- Over 2,600 more neonatal nurses are needed to meet the recommended nursing level – around a 37 per cent increase on current nursing numbers.
- The units in our survey were forced to refuse new admissions for an average total of two weeks in six months.

² Edward celebrates his second birthday in October 2007 and is now going from strength to strength.

³ Whole time equivalent is a unit of measure that is equal to one filled, full time, annual-salaried position.



In 2001, the British Association of Perinatal Medicine (BAPM) published standards which set out the operating practices that neonatal units should follow to ensure that premature and sick babies receive the best level of care. The Department of Health (DH) used these standards to inform their subsequent review and built them into their strategy for improvement.⁴ Neonatal units across the country should aim to meet these standards.

BLISS calls on the DH to ensure that Primary Care Trusts (PCTs) have the appropriate funding and resources to meet these standards.

One key BAPM recommendation specifies the minimum number of nurses that should be provided per cot. This has been calculated to ensure that nurses have enough time to be able to fulfil all of their clinical duties as well as devoting some time to the needs of the families.

BAPM minimum nursing levels⁵

Intensive Care (Level 3): At least one nurse to one baby

High Dependency Care (Level 2): At least one nurse to two babies

Special Care (Level 1): At least one nurse to four babies

A recent study of babies born at less than 1,500g (3lb, 5oz) or less than 31 weeks' gestation showed that when staffing levels are increased to these standards, infant mortality rates within the unit drop by 48 per cent.⁶ This clearly shows that when there are enough staff lives are saved.

Only 15 units told us that in 2005 they operated at or above the minimum nursing levels. What is more, in 2006 this number dropped down to 12. As a proportion of the total 226 neonatal units in the country, this represents only five per cent. This suggests that even those few units that had successfully implemented the recommended standard are now having this progress undermined.

In the 179 units that supplied information about their nursing and cots there is a shortfall of 2,115 neonatal nurses. If these hospitals are representative of the rest of the units in the UK, there is a national shortfall of over 2,600 neonatal nurses.

In the units surveyed, a total net increase of 113 more neonatal nursing posts (whole time equivalent) were created between 2005 and 2006 (see Figure 2). This represents a two per cent increase. However, these units provided over 31,000 more days of care for premature or sick babies in 2006 compared to the previous year. This represents an increase of over five per cent. It is clear from this analysis that demand is outstripping supply.

Not only then has the BAPM compliance rate worsened, but the increasing demand means that there is now further to go to reach the minimum nursing level.

● **When staffing levels are increased to these standards, infant mortality rates within the unit drop by 48 per cent**

⁴ *Neonatal Intensive Care Review – Strategy for Improvement* Department of Health April 2003.

⁵ BAPM 2001.

⁶ Hamilton K E StC, Redshaw M E, Tarnow-Mordi, W. Nurse staffing in relation to risk-adjusted mortality in neonatal care *Archives of Disease in Childhood – Fetal and Neonatal Edition* 2007;92:F99-F103.



● It will take 16 years to reach the number of nurses needed to comply with minimum standards at today's levels

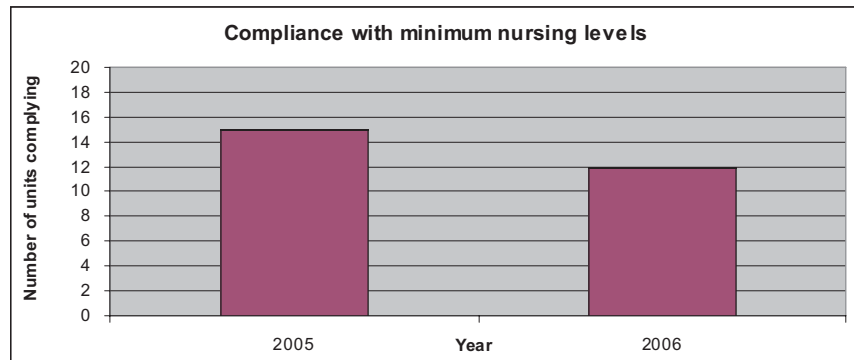


Figure 1

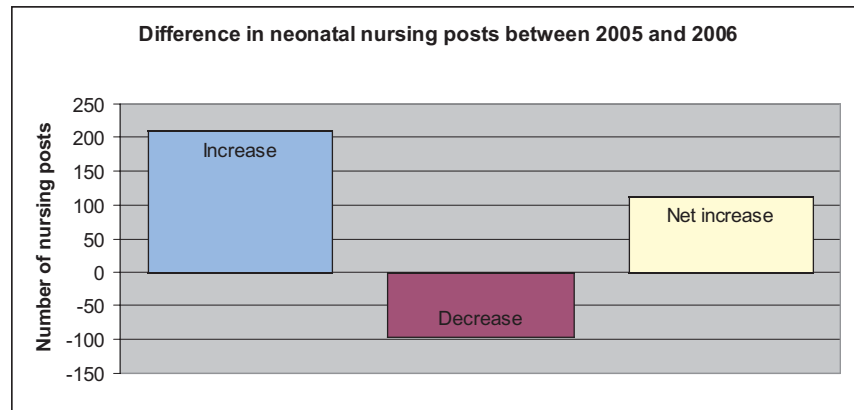


Figure 2

We have seen a steady increase in the number of babies needing neonatal care over the last few years.⁷ An increase in the number of nurses is desperately needed not only to bring staffing levels up to the recommended minimum standard but also to match the increasing demand.

If the increase in nurses that we have seen between 2005 and 2006 continues at the same rate, it will take 16 years to reach the number of nurses needed to comply with minimum standards at today's levels. And this does not take into account the steady increase in demand for cots. If the current rate of increase of nurses does not improve, and demand continues to grow, the minimum standards will never be met and babies' care and safety will continue to be compromised.

Figure 3 demonstrates that there is a wide degree of inconsistency between units. While 81 units have had their number of nursing posts increased, 45 units have had them cut.

In terms of units that had their nursing posts increased by the greatest proportion, the top ten per cent experienced an average nursing post increase of 19.3 per cent. If all the units in the country matched the increase that these units managed between 2005 and 2006, the minimum nursing levels could be reached in less than two years.

This clearly shows that some units are receiving the necessary investment and it is possible for them to increase their nursing numbers. What is needed now is for the DH to compel PCTs to follow these good examples and for PCTs to

⁷ For example, see parliamentary written question answered by Ann Keen MP, Parliamentary Under Secretary for Health Services on 24 July 2007: <http://www.publications.parliament.uk/pa/cm200607/cmhansrd/cm070724/text/70724w0014.htm#0707256000331>



commit themselves to commissioning neonatal care with nursing levels raised to at least the minimum standard.

One method that might help to achieve nationwide compliance with the minimum nursing levels would be the introduction of Payment by Results (PbR) for neonatal care.⁸ This is a relatively recent DH initiative intended to link the allocation of funding for healthcare with the actual activity that hospitals carry out. The key to the success of this system is a specific 'neonatal tariff' adjusted to endorse the BAPM standards. The latest DoH document on PbR, Options for the Future of Payment by Results, advocates using pricing to "encourage adoption of best practice where this will improve quality of care". The research mentioned above reported that when staffing levels are increased to the minimum standard, the infant mortality rate dropped by 48 per cent. This clearly marks a very tangible increase in the quality of care.

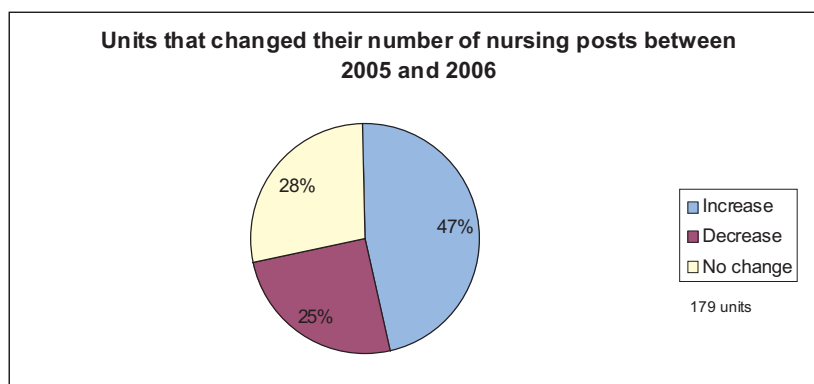


Figure 3

Units can find themselves suddenly overwhelmed as admissions can suddenly soar. One unit reported that one month their cots were 61 per cent full and the next month this figure was up to 116 per cent. To cope with such extreme peaks of activity and to ensure that nurses are able to respond to emergencies, BAPM recommends that the optimum occupancy is 70 per cent.⁹

The results of our survey suggest that 63 per cent of units have a yearly average occupancy above this recommended level. What is more, this proportion is rising, suggesting that the units are being placed under increasing strain.

Furthermore, premature and sick babies can frequently suffer unexpected turns for the worse. Parents often tell BLISS that they have to take things one step at a time, not even thinking about the day ahead when so much can change in just a few hours. Neonatal nurses therefore need to be able to respond quickly to frequent emergencies and this is clearly more difficult if they are already overstretched.

Figure 4 demonstrates how occupancy breaks down across the different levels of unit. It clearly shows that level 3 units are the most overstretched. Over the course of 2006, the average level 3 unit had an average occupancy of 83 per cent – 13 percentage points above the recommended average.

Even more worrying is the admission by eight level 3 units that their average occupancy was 100 per cent or more throughout 2006. This means that during

⁸ More information is available on the DH website: www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/NHSFinancialReforms/DH_077259
⁹ BAPM 2001.



● The scale of the problem is underestimated as a result of nurses and doctors working beyond capacity

the year they provided care for more babies than they were officially designated resources and funding for. This places the staff under enormous strain.

When a baby or expectant mother is in urgent need of care, units will do their utmost to provide the best care they can with the facilities and staff they have available. Sometimes specialist care such as surgery cannot be provided anywhere else and units are forced to go above their occupancy limit as a result.

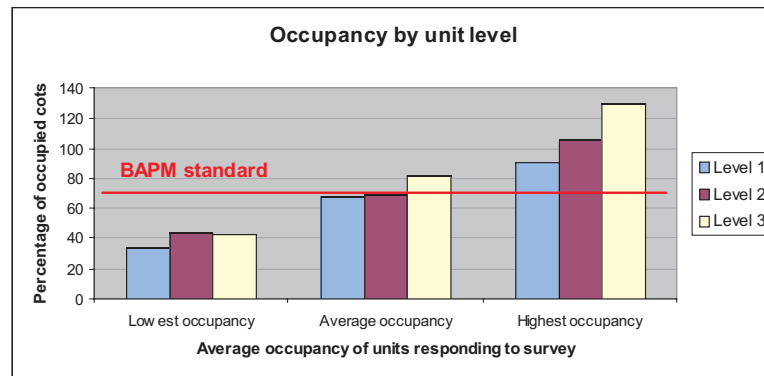


Figure 4

BLISS fully supports the work of the nurses and doctors who provide such vital care but we are concerned that they have to place themselves under such pressure. There is also a real danger that the scale of the problem is underestimated as a result of nurses and doctors working beyond capacity. Professionals faced with too many babies and too few staff often prefer to cope with the situation as best they can rather than highlight the shortage and refuse to take on more work. This of course has knock on effects about the standard of care they are able to provide and the amount of time they can spend with parents. It also has an impact on their ability to keep their skills and knowledge up to date in this rapidly evolving field of medicine.

When units can no longer safely accept any more babies, they have to try to find appropriate cots for new admissions in another hospital. Units try to avoid transferring babies long distances away from their parents' home but unfortunately this sometimes does happen.

BLISS asked the neonatal units for how many days they were forced to refuse new admissions. The units that responded reported that over a six-month period their doors were closed to new admissions for an average total of two weeks.

Ten per cent of units were closed for eight weeks or more. On average the UK's neonatal units are forced to refuse new admissions for an average total of four weeks a year.

The effect is that parents caught in this situation frequently have a traumatic wait while the unit tries to find an adequately equipped and staffed place for them. Parents tell BLISS that on top of the worry about their critically ill child, the confusion over where they are being sent can push their nerves to the limit. Transfers are an essential part of providing neonatal services in the three managed levels of care. However, there can be risks involved in transferring the



most vulnerable newborns. Transfers therefore ought to be arranged either for clinical reasons, such as a baby who needs surgery or a higher level of care, or because a recovering baby can be safely returned to a unit nearer their home. Transfers that take place for any other reason are known as ‘inappropriate’ and often happen for want of a properly staffed cot.

“In many respects, these staff are victims of the system in the same way that [our son] is.”

Many units do not record the reasons behind a baby’s transfer. Those units that did give us data said that they had to make 291 inappropriate transfers in the space of six months. Figure 5 demonstrates the distribution of these transfers and clearly shows that it is level 3 units that are under the most pressure. Seven per cent of level 3 units that responded told us that they had to transfer a baby more than once a week on average because of a lack of properly staffed available cots.

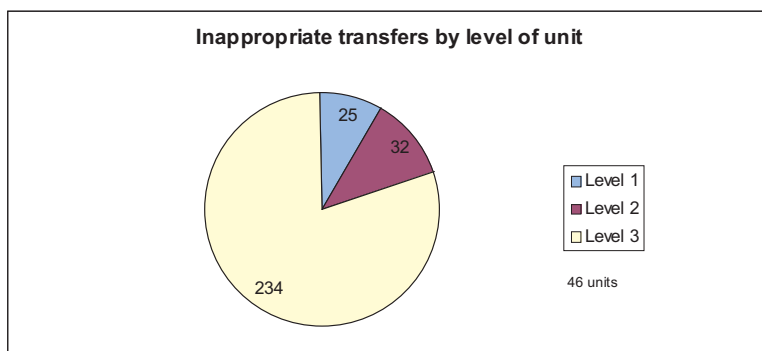


Figure 5

Conclusion

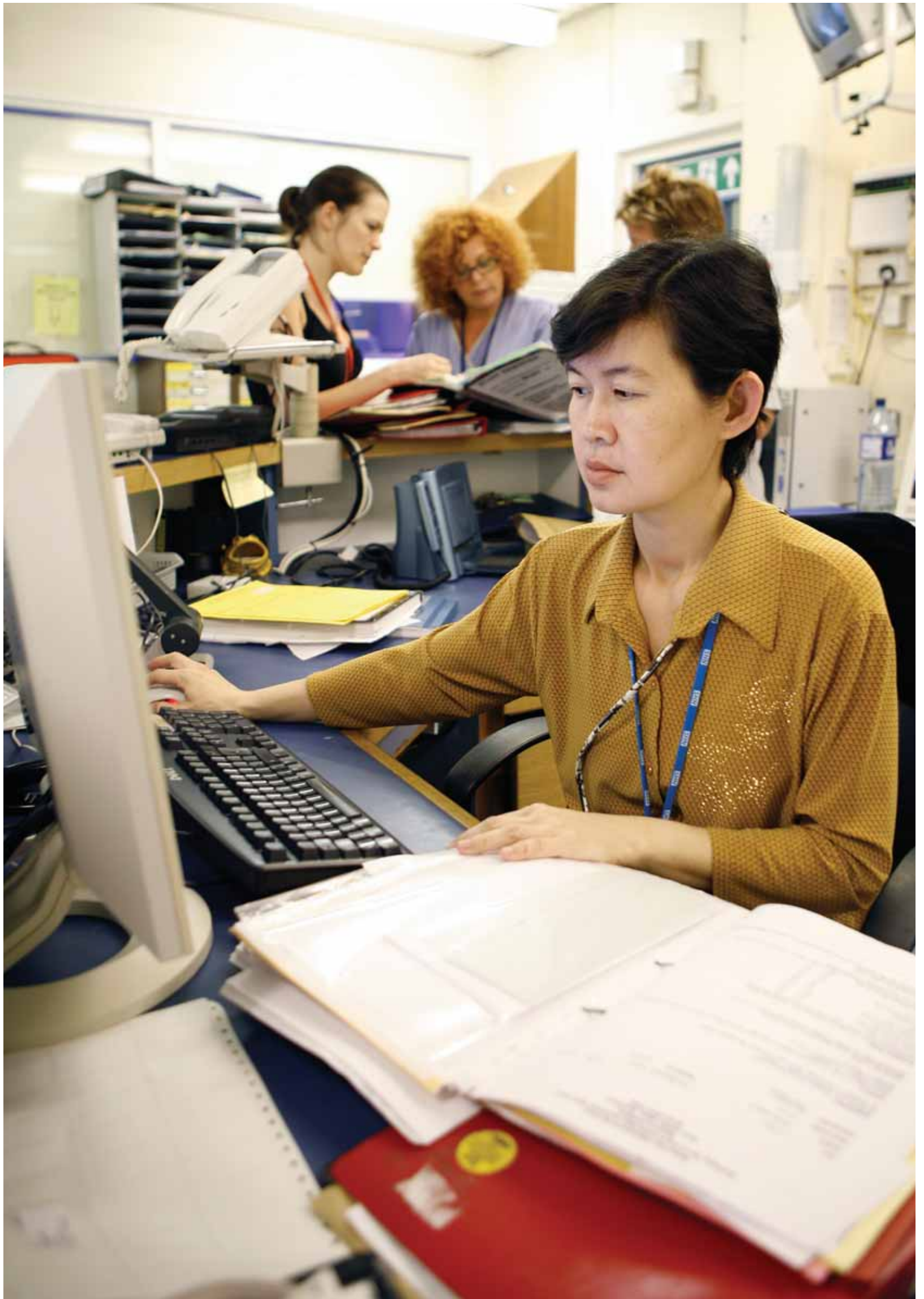
This survey demonstrates that the UK’s neonatal units are in desperate need of more appropriately trained neonatal nurses.

The British Association of Perinatal Medicine (BAPM) was very clear in its 2001 document in stating that babies in Intensive Care need one to one nursing – and the sickest babies will at times need two nurses. They also clearly state that a nurse in High Dependency “should not have responsibility for the care of more than two babies” and in Special Care “should not have responsibility for more than four babies”.

When nurses are forced to go above these levels, which BAPM stated in 2001 “must now be regarded as a minimum standard”, it is inevitable that standards will be compromised. Only 12 units across the UK told BLISS that they meet this minimum standard.

The Department of Health recognised the authority of the BAPM standards when it conducted its Strategy for Improvement in 2003.¹⁰ The Department must now make an explicit commitment to having units implement them. To do this, Primary Care Trusts must be compelled to make the necessary resources available to units.

¹⁰ DH 2003



Clinically managed networks

In 2003 the Government's Review of Neonatal Services recommended that neonatal care in England should be provided within agreed managed clinical networks.¹¹ The report suggested a more structured, collaborative approach for caring for newborn babies. It proposed that hospitals work closely together in formal managed networks to provide the safest and most effective service for mothers and babies. To help neonatal services implement these recommendations, the government made £72 million available over three years.

The role of the network is to coordinate care of premature and sick babies across the three levels of care. The clinically managed network is a group of neonatal units linked together by a supervisory management structure. This allows a regular flow of information around the units and serves to communicate with other networks in the country. This means that up to date information about the number and location of spare cots, details of babies' treatments and transfer arrangements should all be coordinated and shared efficiently. It also allows for the coordination of improved training activities and greater flow of ideas and new techniques which are being developed and improved upon all the time.

Although neonatal networks vary across the country, a typical network consists of around eight hospitals. Within this network there is at least one level 3 unit which can provide the whole range of neonatal care, including Intensive Care for the most critically ill babies, with other hospitals providing high dependency care and shorter periods of intensive care as close to home as possible. The idea behind the network arrangement is that the vast majority of babies should receive treatment within their home network.¹² In most networks this means that no parent should have to travel more than about 30 miles.¹³

Network achievements

A key priority for neonatal networks is to ensure that families are treated as a key partner in the care of their baby – their views and feedback are essential. BLISS has facilitated the appointment of parent representatives to the management board of eight networks and we know that at least 15 networks have some form of parent involvement on their neonatal board.

Parent representatives on the Southern West Midlands Newborn Network Board produced action plans for individual units, participated in a surgical review of the region, started a parent support group and worked with BLISS and another neighbouring network to produce a parent guide to newborn transport.

One of the main advantages of the network management structure is that it allows units to use the funding available to them in a cooperative manner. For example, one network decided to completely refurbish one of its units and invest in raising it to level 3 status to provide Intensive Care service to the whole network. The network also bought two flats to be used as accommodation for families visiting the unit who need somewhere to stay nearby.



● A key priority for neonatal networks is to ensure that families are treated as a key partner in the care of their baby

¹¹ Ibid.

¹² Mr Ivan Lewis MP, then Parliamentary Under-Secretary for Care Services, Adjournment debate Neonatal Care 12 October 2006.

www.publications.parliament.uk/pa/cm200506/cmhansrd/cm061012/debtext/61012-0021.htm

¹³ This is not the case, however, in those networks spread over a wider area such as the South West Peninsula Neonatal Care Managed Clinical Network.



Achievements from other networks include the widespread development of shared protocols for the centralisation of the most intensive care and maximising the capacity of units within the network. The creation of networks has also brought about improved sharing of training and new ideas such as developmental care, a technique which focuses on the baby by responding to their individual needs and responses.

The Cheshire and Merseyside Network set up an education group which developed an induction programme for new members of staff, produced their own workbook and provided back pay to cover study time. This has meant that the network has overcome its recruitment issues and managed to fill all of its vacancies. Another network has been able to coordinate shortfalls across its constituent Primary Care Trusts (PCTs) so as to better manage their finances.

At least three networks established their own dedicated cot management system. This is a service which contacts each unit in the network on a daily basis to check their number of available cots and staffing. This means that staff have live cot availability data and do not need to ring around units to find an empty cot when a baby needs to be admitted.

Going home with baby

The role of the community neonatal nurse is to help parents make the difficult transition between having a baby on a Special Care unit and caring for them at home. It makes it easier for units to send babies home when they know that a community neonatal nurse will be able to give parents advice and visit them at home to make sure everything is alright.

Unfortunately, the number of community neonatal nurses is in decline since they are frequently vulnerable to budget cuts.

The North Central London Perinatal Network has come up with an innovative idea to tackle the situation. They have taken some of the Department of Health development money for neonatal networks to fund a number of new community neonatal nurses. They also plan to introduce a rota system which will see neonatal nurses spending a month at a time working alongside the full-time community nurses across the network.

This means that they can provide expert help to parents of premature and sick babies, many of whom they will already know from their time on the unit. It also gives the nurses a break from the highly stressful environment of the unit and allows them to see the success stories of their work – babies who they have seen fighting for their lives on the unit who have finally gone home with their family.

This network should be praised for coming up with a new way of providing a better service to babies and their families. However, this additional improvement should not be seen as a substitute for having the minimum nursing levels implemented.



● **Networks have helped to deliver distinct improvements across England**

In November 2006 the Department of Health (DH) launched the National Cot Locator. This linked the cot management systems that already existed and set up new systems where they did not. Designed to facilitate the transfer of babies outside the local network when necessary, this system potentially helps with the provision of joined up neonatal services.

The network configuration also allows managers to forge more integrated working arrangements with the related disciplines of maternity and obstetrics. In some areas this has been brought about by the creation of a perinatal network structure which aims to incorporate all services relating to care of the mother and newborn. Amongst others, the London networks, the Staffordshire, Shropshire and Black Country Newborn Network and the Bedfordshire and Hertfordshire Perinatal Network have all made progress towards this aim.

On top of the recommendations of the Government's 2003 Review, the network managers have also organised a national forum to share ideas and developments and to improve coordination between all the networks.

Conclusion

BLISS strongly supports neonatal networks and we believe that networks have helped to deliver distinct improvements across England. Networks have brought about improvements in staff training, developments in transport systems, improved patient flow between units and have helped to identify variations in practice. Neonatal services in the rest of the UK would do well to adopt some of the best practice that has been developed through the introduction of networks in England.

However, neonatal networks are a long way from fulfilling their full potential. Networks continue to face uncertainty over their future and network managers are often hired on short-term contracts. As a result, many of these posts have been left unfilled and others were only contracted until April 2007. Having a vacant managerial post clearly has a detrimental impact on the network's performance as it misses out on opportunities to participate in the development of best practice. Furthermore, as long as the network manager post remains vacant in some networks, coordination between networks will not function on a truly national basis and individual units will inevitably suffer as a result.

The original funding allocated in 2003 by the DH to help establish neonatal networks was insufficient to support all the developments required. In the financial year 2004/05 this funding was subsumed into the baseline budgets of PCTs and neonatal networks and services had to compete for this money alongside the PCTs' other priorities. Although some networks have managed to secure further funds over a number of years, others have not and this naturally contributes to a degree of instability, particularly over the funding of the network infrastructure.

If networks are to be successful, they need clear commitment and support from PCTs. The DH should recognise the obvious achievements that networks have had and mandate PCTs to give them the long-term planning and resources they need. Only then may clinically managed neonatal networks overcome the future uncertainty they face and continue to make progress.



Neonatal transport

Neonatal transport is an essential element of neonatal care. The transfer of babies between units, especially with the establishment of clinically managed networks in England in 2003, is an everyday occurrence in neonatal care. For example, babies are often moved from level 1 to level 3 units to receive the specialist care such as surgery that those units provide, and will often be repatriated to their original unit when the baby's condition has stabilised. It is therefore surprising that neonatal transport systems in the UK are underdeveloped. In our report *Weigh less, worth less?* (2006), we reported that there was a wide variation in transport services across the country.

Transferring a premature or sick baby clearly requires specially trained staff and purpose-built equipment. BLISS has called for the creation of dedicated transport teams in each network so that units are not deprived of nurses while they are engaged in transferring a baby from one unit to another. Specially equipped ambulances should also be used to avoid delays due to ambulance and equipment availability. Transfer is also a time of great anxiety for parents so staff need to be available to explain what is happening and provide reassurance.

“Once an ambulance was secured, staff had to be found to cover the transfer so it was held in the balance until a doctor and nurse agreed to the overtime.”

BLISS has identified certain areas where developments have been made and specific systems set up for neonatal transport. This chapter discusses some examples where progress is being made. This contrasts with the rest of the country, however, as most areas of the UK have no system in place and transport is arranged on an ad hoc basis. Improvements have been made since our last Baby Report and this is largely due to the work of neonatal networks and their concentration on improving integration between units.

England

The London, Kent, Surrey and Sussex Neonatal Transfer Service (NTS) was initiated in 2003 as a direct result of extra funding from the Department of Health (DH) for neonatal care. In the four years since its establishment, the NTS has become a beacon of good practice for transport services. It plays a key role in the provision of high quality neonatal care across London and the South East.

In conjunction with BLISS, NTS produced a questionnaire in 2005 asking parents about their experience of transfers. This led to an information pack being produced for parents, answering frequently asked questions about transfers and providing useful information on the unit to which their child was being transferred.

This involvement of parents in the transfer of their child is vitally important. While health professionals and commissioners understand the need for transporting babies to appropriate care, often the parents are unaware of the



● **Involvement of parents in the transfer of their child is vitally important**



● **Without dedicated transport teams, units are deprived of their staff while the transfer is taking place**

reasons behind the transfer. To help alleviate this problem, Staffordshire, Shropshire and Black Country Newborn Network produced an information leaflet for their Newborn Transport Service, in collaboration with BLISS, explaining the reasons behind transfers, what parents could expect and how the baby will be transported.

The Greater Manchester, East Cheshire and High Peak Neonatal Network has purchased a dedicated staff transport vehicle. This removes the need for an ambulance to spend time waiting for medical staff to stabilise a baby ready for transport. Instead, staff can be transported to the baby's location, make preparations for the transfer and then call the ambulance only when the baby is ready.

The East of England Acute Neonatal Transport Service started operating in June 2003. This was a direct result of the review of neonatal services across the east of England and in recognition that a dedicated transport system was needed to provide emergency transfer service. This service however lacks the dedicated funding to provide a 24/7 service essential to maintaining the safety of all the units within the network.

BLISS advocates the introduction of a separate Payment by Results (PbR) tariff for transport. This needs to be 'unbundled' from the overall tariff for different levels of neonatal care to provide an incentive for commissioners to invest in these essential services that may otherwise be ignored or under funded. For more on PbR, see the chapter on neonatal care on page 13.

Wales

Wales has an underdeveloped transport system which functions on informal, ad hoc arrangements. Whereas the development of neonatal networks and investment from the DH has resulted in improvements across the board in neonatal care in England, the picture in Wales is bleaker. The pace of change has not matched that in the rest of the UK and clinical networks have not been introduced. Neonatal care is still arranged in the historical context of a regional centre and supporting sub-regional units.

Without dedicated transport teams, units are deprived of their staff while the transfer is taking place. To add to this, there are frequently difficulties over ambulance provision, as there is no special arrangement for the transport of premature and sick babies.

Northern Ireland

Until now, neonatal transport has been organised entirely on an ad hoc basis in Northern Ireland. Progress is now being made, however, with the development of a dedicated transport service. Funds have reportedly been allocated for one doctor and a part-time neonatal nurse and a plan for the transport system is currently being devised.



Scotland

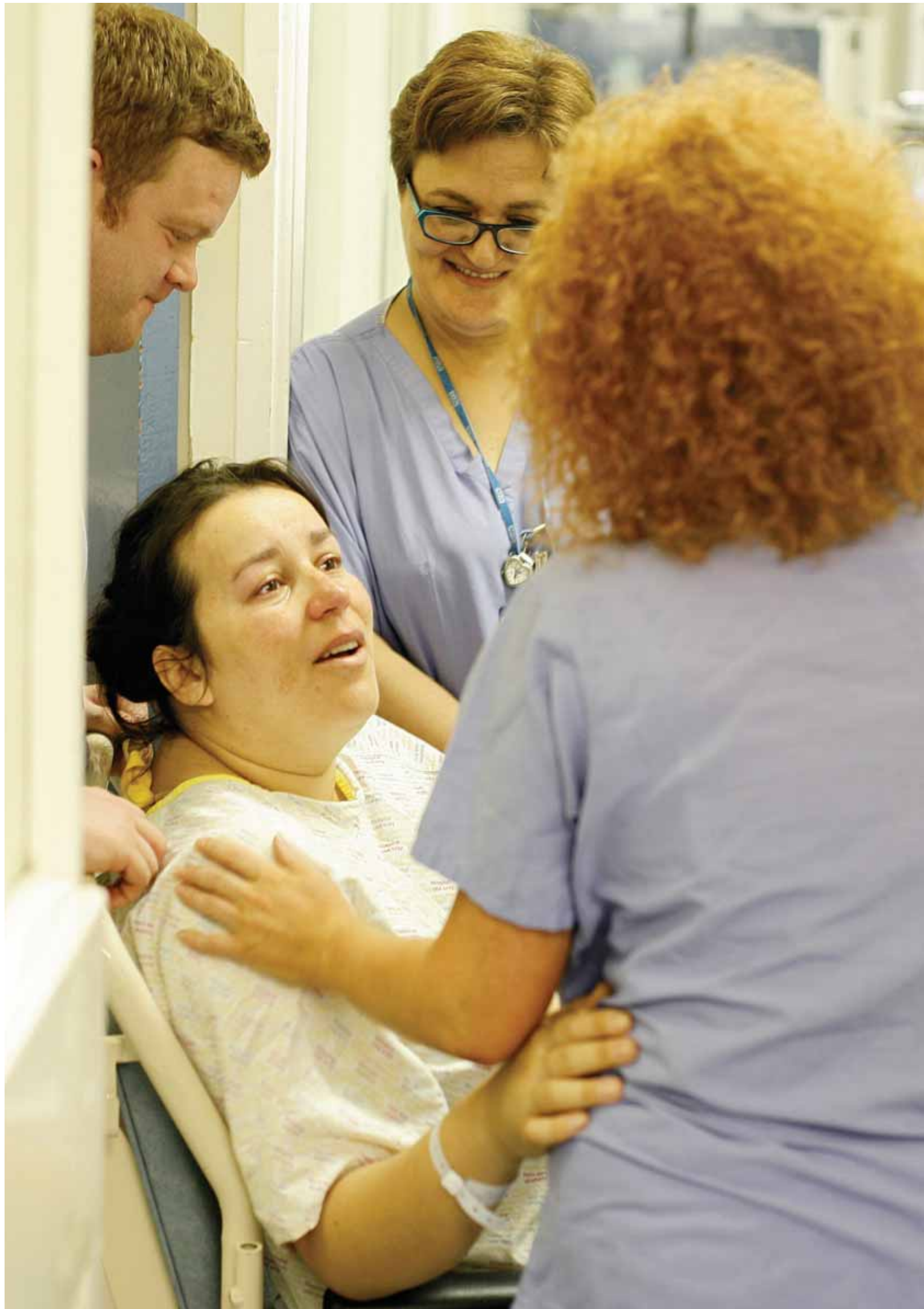
The situation is better in Scotland thanks to a dedicated neonatal transport system that is lauded across the UK. Transport is organised into three regional teams with four host sites: Aberdeen and Dundee for the northern region, Edinburgh in the southeast and Glasgow for the western service.

The service has pioneered improvements in neonatal transport, from training to equipment. In September 2005 the service introduced dedicated ambulances, equipped with appropriate equipment for the safe transfer of babies. The service, in conjunction with the Scottish Air Ambulance Service has also developed and designed equipment for dedicated fixed wing and helicopter aircraft. This equipment has received air certification and is now in operation.

Over six years 146 staff including nurses, medical staff and paramedics have received specialist training in the transport of babies. Furthermore, the Scottish Transport Network has a central computer database of transfers that personnel from all three regional teams can access. Discussions are now underway with all UK transport teams with a view to standardising their systems to ease information sharing.

Conclusion

The lack of a dedicated neonatal transport system is one of the key contributing factors to units being forced to work above their capacity. An efficiently coordinated transport system is the foundation upon which the concept of a managed clinical network is built. It allows babies to be transferred to the appropriate level of care at the right time. If transport is not available, it can lead to babies occupying cots that are not appropriate to their condition. This in turn leads to those cots being unavailable to babies who need them. Without the availability of neonatal transport a unit loses its ability to function as part of an integrated system of neonatal care.



Parents' experiences

BLISS conducted an online survey to ask parents about a range of neonatal care issues. The results reveal the immense cost that having a premature or sick baby can have to parents both financially and, of course, emotionally.



● Thirty-five per cent of parents of twins reported that their children received treatment in separate hospitals

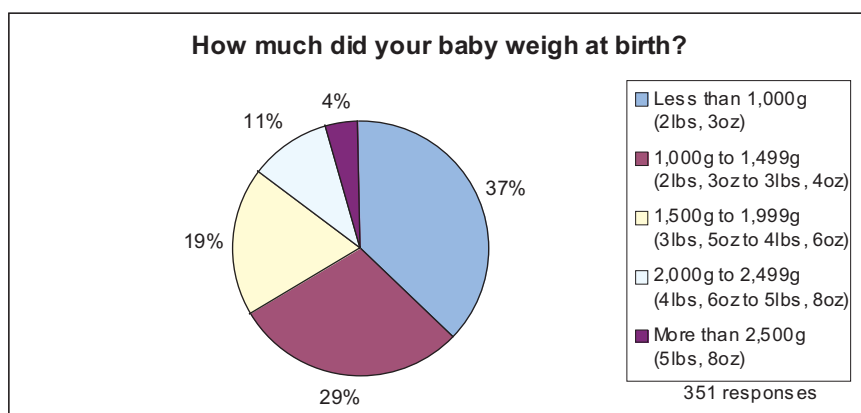


Figure 6

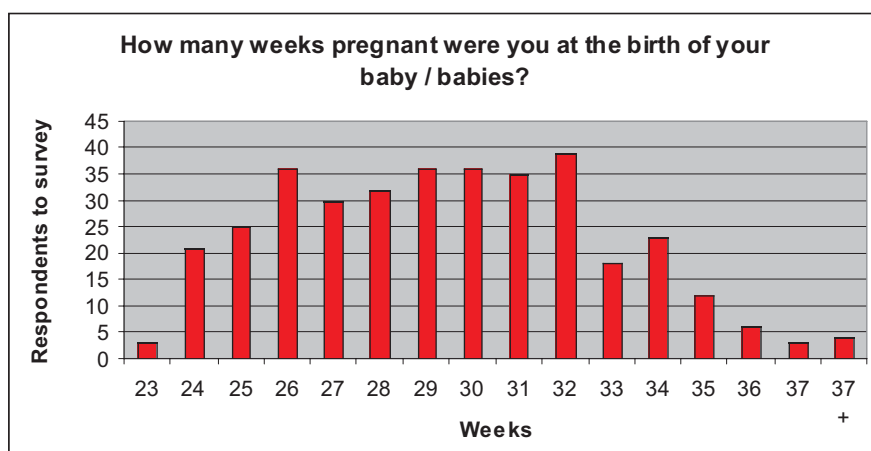


Figure 7

A quarter of parents had their babies transferred from one unit to another. Thirty-eight per cent of these had not been informed prior to the birth that this might happen.

Seventeen per cent of parents surveyed had to travel over 30 miles to see their child and the average daily travel cost for parents was £9.17. The mother of a premature or sick baby may often need medical treatment and recovery. Her partner may well have to hold down a job at the same time as visiting their sick newborn and caring for the mother. This daily commute is an added stress.

A greater proportion of multiple births involve complications such as prematurity or low birthweight than singleton births. Often the reason why sibling babies cannot be treated together is a lack of adequately staffed cots. This underlines how the investment in nurses, discussed in the first chapter, is so desperately needed. Thirty-five per cent of parents of twins reported that their children received treatment in separate hospitals. Having a baby born prematurely or sick is already a traumatic experience without having to spend time commuting between different hospitals.



“I saw Polly when she was a day old. It was horrible, the NICU was full... I was in a wheelchair and couldn’t get near her. I felt in the way.”

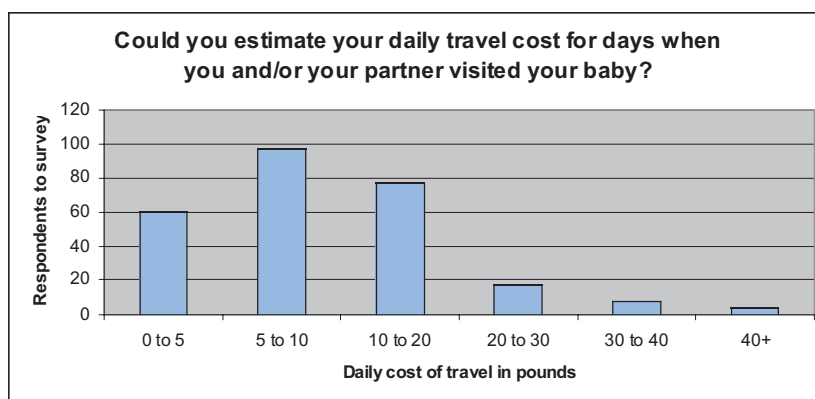


Figure 8

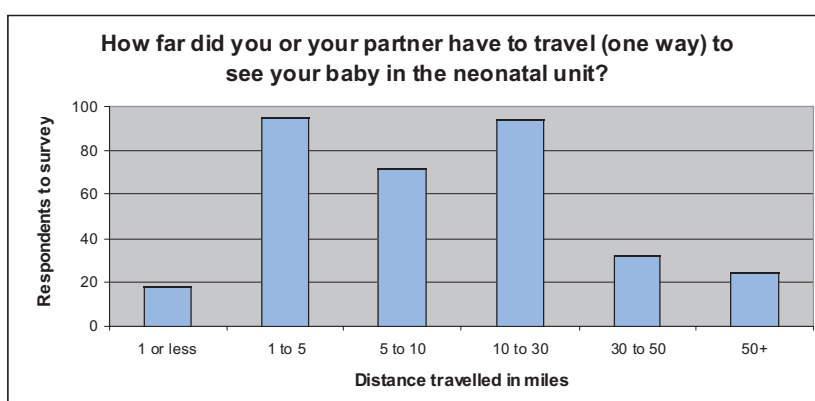


Figure 9

Having access to information is one of the most important things for new parents whose baby needs neonatal care. The more that a parent knows about what is happening, the more they are likely to feel in control of the situation. An excellent example is the website of the Peter Dunn Neonatal Intensive Care Unit which has been designed to address a wide range of parents’ concerns and questions.¹⁴ Many parents tell BLISS that being shown around the neonatal unit before their baby is admitted helps ease their worries about what lies ahead.

Figure 10 shows that most mothers find out that their child will need neonatal care when they are actually in labour. Many premature births are unexpected, so the improved identification of at-risk mothers would enable parents to be better informed about neonatal care earlier. This should provide reassurance and make them feel more involved in the care of their baby. This highlights the importance of bringing maternity, obstetric and neonatal services into a closer working relationship.

“No hospital they rang had two cots available so Daisy and Archie had to be split up. This was the most traumatic part of the whole experience.”

¹⁴ www.ubhtnicu.com

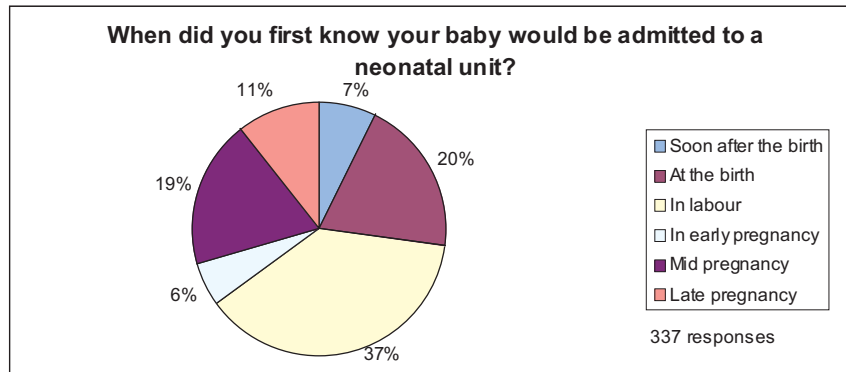


Figure 10

Some results of the survey were encouraging. For example, 67 per cent of parents felt that their child's problems were always discussed with them and 61 per cent felt that equipment and procedures were always explained to them. However, almost half (48 per cent) of parents felt that they were not given enough time to ask questions about the care of their baby. Only four per cent of parents were aware that neonatal care is organised into networks and 58 per cent of those whose babies were transferred did not know whether the transfer took place within the same network.

“[The nurses] noticed that I was very shocked by all this going on and suggested my husband went for a look around the NICU/SBCU – as I was told to stay in bed. They gave me the BLISS Parent Information Guide and my husband came back and told me what it was like. He felt so much better after seeing the unit, which then put my mind at rest.”¹⁵

In the unfamiliar environment of the neonatal unit, it can be very hard for new parents to feel like proper mums and dads. Table 1 gives details of parents' responses to the survey question of how they felt they were treated by staff on the unit. Over half of parents thought that staff on the unit were always or sometimes critical of them (53 per cent), and 63 per cent felt that they had been in the way at some point. Only 46 per cent of parents thought that staff were always aware of their needs. However, 69 per cent felt that they were always able to sit by their baby for as long as they wanted.

Table 2 demonstrates what parents told us about the facilities that were available to them. Doctors consider the provision of such facilities to be the very bare minimum. It is shocking that 31 per cent of parents said there was no accommodation for mothers and 43 per cent said there was no accommodation for both parents.

Ninety-one per cent of mothers had access to a room in which to breastfeed or express milk. While this is clearly an improvement, having a quiet private space to breastfeed or express milk is such a basic requirement that anything short of 100 per cent is unacceptable.

¹⁵ From the BLISS online parent message board: www.blissmessageboard.org.uk



When you visited your baby in the neonatal unit, did you feel... ¹⁶	Always	Sometimes	Never
...able to sit by your baby as long as you wanted?	69%	28%	2%
...that you could have skin to skin contact with your baby?	28%	50%	21%
...that you were in the way?	6%	57%	37%
...that staff were critical of you?	11%	42%	47%
...included in your baby's care?	64%	33%	3%
...that you had adequate support with breastfeeding or expressing breast milk?	49%	35%	16%
...that the staff were aware of parents' needs?	46%	49%	5%

Table 1

Were the following facilities available for you as parents?	Yes	No
Accommodation for mothers in or next to the neonatal unit?	69%	31%
Accommodation for both parents in or next to the neonatal unit?	57%	43%
Tea and coffee making facilities?	73%	27%
Room for breastfeeding or expressing?	91%	9%

Table 2

Nearly three quarters (73 per cent) had access to tea and coffee making facilities. Such concerns may seem minor compared to the more pressing issue of caring for seriously ill babies, but privacy and time to think is a rare commodity in the hectic environment of a neonatal unit.

There are also improvements to be made in the way in which parents are involved in their baby's care. Innovations such as Kangaroo Care are still in their infancy as 21 per cent of parents reported that they were never able to have a cuddle with their baby in the neonatal unit.

“Having Kangaroo Care was amazing! It really helped us bond with Ben, my wife just loved doing it.”

¹⁶ Percentages may not total 100 per cent due to rounding.



Kangaroo Care is skin-to-skin contact when a baby is placed against its parent's chest, like a young kangaroo in its mother's pouch. Benefits of this type of contact can include improvements with establishing breastfeeding and lactation, a more regular heartbeat and increased oxygen level for the baby and, in the longer term, improved weight gain and sleeping patterns. Kangaroo Care can even be carried out when babies are on Intensive Care equipment but may not be suitable for all babies at all times and does need careful planning with the nurses.

● The vast majority of parents are incredibly grateful for the expert care that their baby receives in the neonatal unit

Parents often tell BLISS that they only felt that their baby was truly theirs when they returned home. This can often lead to mums and dads having problems bonding with their child. The vast majority of parents are incredibly grateful for the expert care that their baby receives in the neonatal unit. However, they would also appreciate closer contact, both physically and emotionally, with their baby in its first weeks.

“I felt like I wasn't a mummy as I had no say or control over the care of my babies.”

Parent conclusion

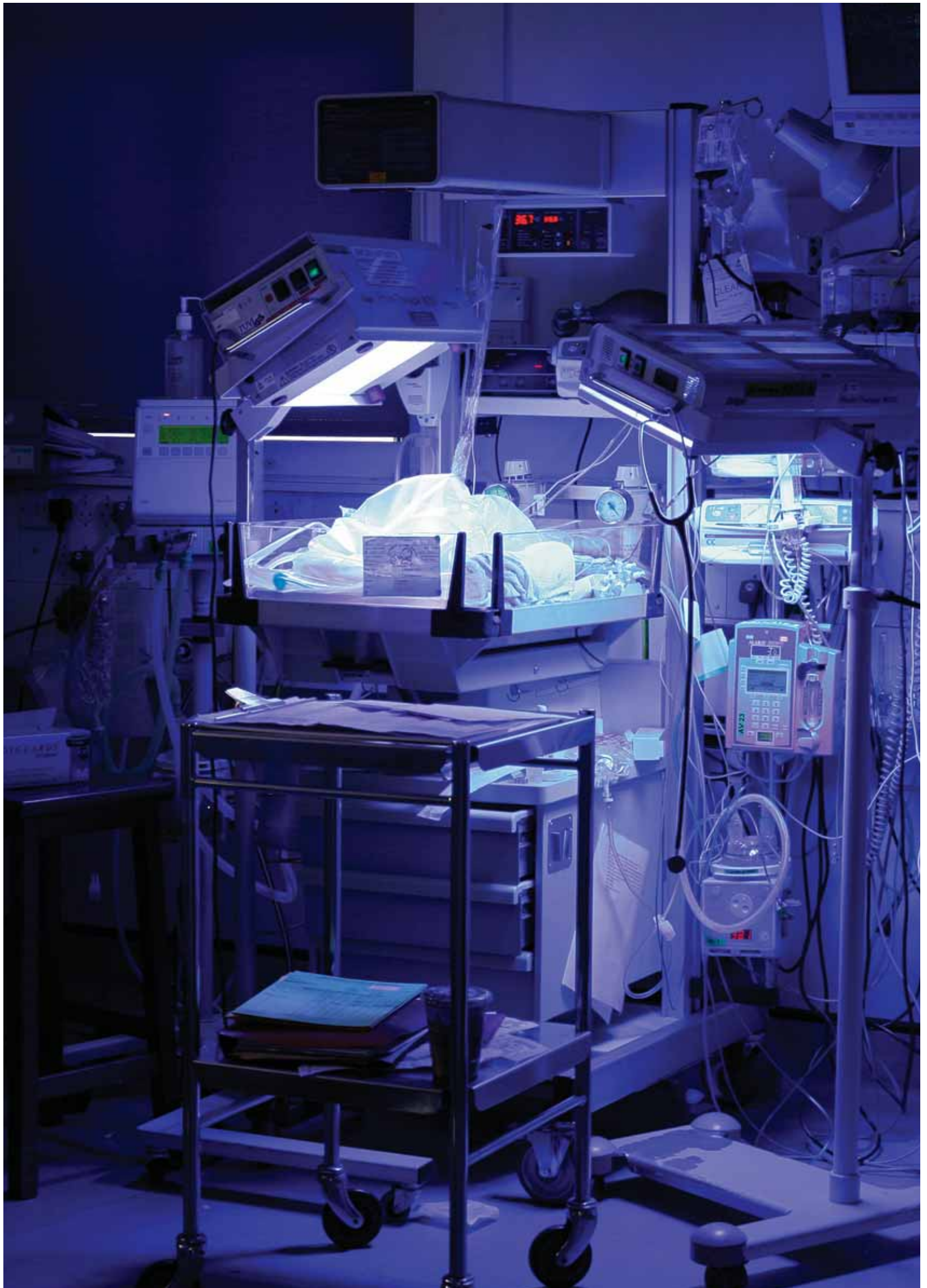
This survey shows that great work is being done on neonatal units to consider the needs of parents and involve them in their baby's care. It is clear that medical staff put a great deal of effort into explaining what is happening and some improvement has been made in the provision of facilities.

However, there is still a long way to go. The key areas for improvement are communication and the timely provision of information. In particular, earlier identification and provision of information for at-risk parents, earlier and clearer information about transfers and how neonatal networks affect the care of babies.

The provision of basic facilities also continues to be an issue. The main areas of concern are accommodation for families and facilities for breastfeeding and expressing milk.

More work could be done to consider the softer side of care. This could be as straightforward as considering that parents are in distress and do not feel in control of their baby's care. Simple steps, such as getting parents to decide what clothes their baby will wear, have been shown to help this. Kangaroo Care is also a great way to build the parent-baby bond and this technique should be encouraged whenever possible.

The one factor which underpins all of these necessary improvements is the number of appropriately trained neonatal nurses. If the recommended minimum level of nursing were reached, nurses would have the time to devote to these key areas.



Conclusion

As this report demonstrates, neonatal nurses, doctors and managers tell BLISS that their struggle to provide the minimum levels of care is caused by a shortage of staff. All of the other concerns and problems that this report raises stem from this shortage of qualified neonatal nurses.

The reasons for this shortage arise from the Department of Health's (DH) failure to make the British Association of Perinatal Medicine (BAPM) minimum nursing standard compulsory and to give Primary Care Trusts (PCTs) the resources to implement the standard.

Of the three levels of care, it is primarily the level 3 Intensive Care units which are feeling the greatest pressure. Level 3 units have the highest average occupancy rate and were forced to conduct the vast majority of inappropriate baby transfers.

As a result of the challenges which neonatal services have faced in the last few years, the National Audit Office is currently conducting an audit of neonatal services to look at the value for money that they provide. We await their findings early in 2008.

PCTs tell BLISS that recruiting qualified neonatal nurses is difficult because of a lack of new entrants into the system. Although neonatology is an immensely rewarding branch of nursing, it is also one which takes its emotional toll as the work of a neonatal nurse inevitably involves seeing babies suffer and sometimes die.

This is made much worse when nurses are forced to work in conditions that are understaffed and under-resourced. Nurses cannot afford to spend as much time as they should with the parents, talking to them, explaining the situation and providing reassurance. Parents are a crucial partner in the care of a critically ill baby and yet, because of staff shortages, they can end up feeling in the way.

Standards of care have been widely implemented for children and adults but not for babies. The time has come for the DH to formally endorse the BAPM standards and mandate PCTs to bring the quality of care for babies into line with that for children and adults.





Recommendations

- The Department of Health must mandate Primary Care Trusts to implement the standards set by the British Association of Perinatal Medicine in 2001 (see page 11).
- The Department of Health must ensure that Primary Care Trusts have the appropriate funding and resources to meet the standards.
- Primary Care Trusts must fully implement the standards as a matter of urgency.
- The Department of Health must introduce Payments by Results for neonatal care with separate tariffs for neonatal transport and each of the three levels of neonatal care, topped-up to endorse the standards set by the British Association of Perinatal Medicine.
- The Department of Health must support the establishment of dedicated round-the-clock neonatal transport across the country.
- Primary Care Trusts must support neonatal networks and ring-fence their funding to allow them to continue their good work.
- The various disciplines connected to maternity care must forge closer working relationships and better identify high-risk parents so as to provide them with earlier and clearer information about the neonatal care services available.
- All neonatal units must work to provide better facilities, such as a room for breastfeeding or expressing milk and overnight accommodation, for parents of premature and sick babies.

Methodology

BLISS sent a request for information under the Freedom of Information (FOI) Act 2000 to every hospital in the country with a neonatal unit. We asked a series of questions about their admissions, staffing levels and capacity in the years 2005 and 2006. We received responses from 195 units (86 per cent). The figures quoted have therefore been supplied to BLISS by the neonatal units themselves. In accordance with the spirit of FOI, BLISS only sought to collect information which neonatal units already collect and have readily available. No unit answered every question so the number of answers per question varies from 111 to 187.

Previous BLISS reports, including *Special care for sick babies... choice or chance?*, *Weigh less, worth less?* and *Special delivery or second class*, were produced with the National Perinatal Epidemiology Unit at Oxford University. This report has been produced independently, however, using a different research methodology. Therefore, we have deliberately not drawn direct comparisons between previous reports and this one since this would not be statistically valid.

The chapters on neonatal networks and transport are a review of literature and reports supplied to BLISS by health professionals. Most neonatal networks produce some form of annual report or update and we have used these to find examples of promising developments and best practice. Additional information on networks and transport has been kindly supplied by individuals in the field of neonatology.

In February 2007 BLISS posted a survey on our website asking parents about their experiences of neonatal care. We received 357 responses, from a range of parents with different experiences of neonatal care. We asked parents to reply to 22 questions about a range of neonatal care issues, from the transfer of babies to facilities for parents such as overnight accommodation and privacy to express breast milk.





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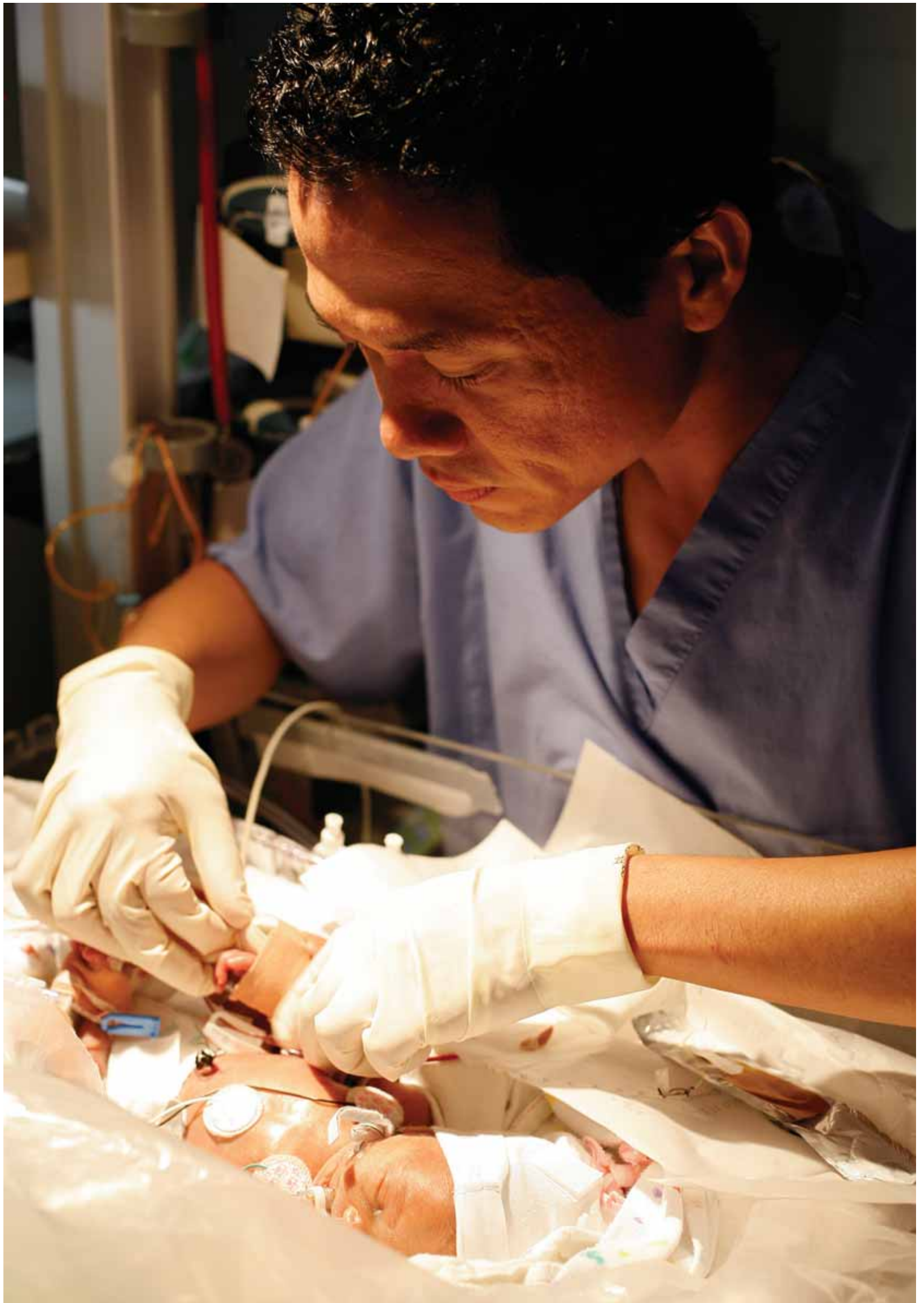
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