Weigh less, worth less?

A study of neonatal care in the UK

BLISS Baby Report 2

THE PREMATURE BABY CHARITY

BLISS

Acknowledgements

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BLISS commissioned Dr Maggie Redshaw and Dr Karen Hamilton of the National Perinatal and Epidemiology Unit (NPEU) at the University of Oxford to undertake the research. All those seeking to quote or make reference to this report should, where appropriate, both acknowledge this report and the work of Dr Redshaw and Dr Hamilton.

A report of the research by the NPEU will be available on their website in Autumn 2006 at www.npeu.ox.ac.uk

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Contents

Foreword

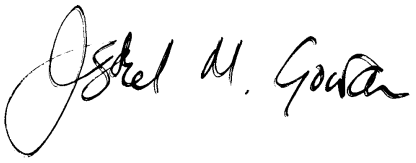
I am pleased to introduce the second BLISS Baby Report, *Weigh less, worth less?*. This report follows our Baby Charter, launched last year, which recognises that babies are individual human beings with all the rights and entitlements that people of all ages enjoy (see Appendix A). These are the standards we aspire to for all babies.

Our first report revealed a neonatal service overstretched, under-resourced and slow to respond to promising innovations in care. We therefore decided to look again at neonatal care, in particular at staffing and transfers – the aspects of the service that can mean the difference between life and death. It is frustrating that our second report shows the service has got worse in terms of availability of staffed cots.

We do not want to keep producing reports every year that shows the NHS is failing to meet the needs of sick and premature babies. Instead our aim is to call to account the decision makers who plan, design and fund the NHS neonatal service and ask if it is really acceptable that babies, unlike adults, are transferred across the country in search of a staffed bed?

While the NHS is undergoing a process of unprecedented change, our position is not to simply oppose change but to ensure that where change is happening, it delivers improved patient care for sick and premature babies. Inequality for babies has been institutionalised in a system that provides one to one nursing care for adults in intensive care but denies this to vulnerable infants. Payment by Results and the reform of commissioning present an opportunity to break with the past. However, these reforms must not be concerned with cost cutting, but be implemented in a way that seeks to invest in these young lives.

I hope you find the report informative. I ask you to remember that behind the statistics are families struggling to come to terms with the unexpected arrival of their baby. We also pay tribute to the hardworking neonatal staff and their perseverance in the face of the funding crisis revealed by this report.



Isobel Gowan
Chair of Trustees

Executive summary

Neonatal care resources

Neonatal care is in crisis with an increasing number of units forced to close to new admissions because they do not have the staff to care for more babies.

- On average 78% all units had to close to new admissions at least once in the last six months – this is worse than last year.
- The most severely affected were Level 3 intensive care units where 90% had to close to new admissions – this is worse than last year.
- Only 3% of units can meet the standard of one nurse to one baby in intensive care – no improvement compared with last year.

Transfers of mothers and babies

Babies are continuing to be transferred around the country in search of a staffed cot because of a lack of capacity. Not only does this cause emotional stress for parents, it can have a financial impact too.

- Networks in England reported that, on average, a baby was transferred out of the network almost every three days.
- Babies in these networks were transferred an average farthest distance of 126 miles.

Neonatal networks

Neonatal networks are working well in furthering collaboration between different units leading to shared training programmes for staff and the promotion of best practice. However, they are less successful at managing the flow of babies between different types of cot. Networks are hampered by a lack of resources and continuing debates around the formation of the network.

- 87% of parents did not know that neonatal care was organised in neonatal networks.

Mortality rates

While overall the number of babies dying before their first birthday is going down, there are wide differences in infant mortality between different parts of the country and between different social groups, despite a government target to reduce these inequalities.

- A baby is eight times more likely to die before their first birthday in central Birmingham than in mid-Surrey.
- A baby is seven times more likely to die before their first birthday in Inverclyde than in Caithness.

Introduction

Having a baby is a great time of celebration and joy for most families. All new parents go through a rollercoaster of emotions and experiences. This is equally true for parents of babies that are born earlier than expected or who are born sick. The birth of their baby is cause for congratulations. However, it can also be a frightening and bewildering time, as expectations are thrown out of the window.

Having a baby spend time in a neonatal unit is a surprisingly common experience as this affects one in eight babies, and it looks set to become even more commonplace. Recent studies[1] show the number of premature babies being born is rising.

This is partly due to a number of social trends (women delaying childbirth to later in life, rise of fertility treatment and multiple births, and the number of teenage mothers) that may often lead to complications in pregnancy and babies needing extra health care. It is also a consequence of advances in medical care, resulting in increasing numbers of premature babies surviving. As more babies need neonatal care, so it becomes ever more important to ensure the neonatal service can cope with this increase in demand.

This report is a study of the provision of health services for sick and premature babies in the UK today. This is the second BLISS Baby Report and follows on from our first report *Special care for sick babies – choice or chance?* published in July 2005[2] which examined all aspects of neonatal care. The scope of this second report is more focused and will look in depth at the resources available in neonatal units and its impact on babies and their families.

While a Government review of neonatal services in 2003 acknowledged that babies in intensive care should receive one to one nursing (which is the level of care adults receive), this was not made mandatory and therefore is not surprising that most neonatal units do not operate at this level.

We are campaigning to achieve similar levels of funding and staffing for babies in intensive care compared to funding provided for adults in intensive care.

Our report will look at the level of staffing in neonatal and also the consequences of inadequate resources – transfers of mothers and babies to find cots.

In particular, this report focuses on the organisation of services now that managed clinical neonatal networks have, for the most part, been in operation in England for the last two years.

This report will examine what difference, if any, networks have made to the care of sick and premature babies. It will look at what can be learnt from this experience for the other home nations.

[1] Editorial: *Why should preterm births be rising?* BMJ Volume 332, pp924-5, 22 April 2006.
[2] *Special care for sick babies – choice or chance?* BLISS July 2005. This can be accessed at www.bliss.org.uk and the NPEU research which formed the basis of this report can be accessed at www.npeu.org.uk

As outlined in our Baby Charter, BLISS believes that all babies, regardless of the place or circumstance of their birth, should have an equal chance of survival and the best quality of life. Through examining regional and local variations in the numbers of babies dying before their first birthday, this study will also look at inequalities in outcomes for sick and premature babies in the UK.

BLISS commissioned Dr Maggie Redshaw and Dr Karen Hamilton of the National Perinatal Institute (NPEU), based at the University of Oxford to carry out several pieces of research which form the basis of this report.

Firstly a survey was sent to all neonatal units in the UK asking a number of questions concerning their capacity and organisation (64% response rate). Secondly a similar survey was sent to all network managers in England on the operation of the network (100% response rate).

In order to gather a full picture of neonatal care, a survey for parents was placed on the BLISS website and 216 complete surveys were analysed. The survey was designed by NPEU in consultation with BLISS.

The parent survey is not a representative sample of all parents of sick and premature babies. The analysis shows we had a higher than average response from parents who gave 'white' as their ethnicity (98%) and a higher than average response from mothers aged 26 to 35 (66%). Our sample also includes a higher than average response from families whose babies were born very premature or sick (49% of babies were born at less than 30 weeks gestation). However it does still give us a hugely interesting insight into the experiences of mothers and families, from which we can draw important conclusions. Given that the large number of people who responded to our survey had a baby born at less then 30 weeks, this will provide us with useful information about the experiences of parents who spent a significant time in the neonatal unit.

The NPEU have provided preliminary results and they will publish a full report to be made available on their website later in the year.

This report therefore contains highly credible evidence of the state of health services for sick and premature babies. It is intended to be used primarily to help policymakers take decisions on the operation and resourcing of neonatal care. It is also highly relevant to health professionals and families.

We will make a number of recommendations to decision makers that can point the way to how we can make sure all our sick and premature babies have the best start in life.

Chapter One

Neonatal care resources

- **On average, 78% of all units had to close to new admissions at least once in the last six months – this is marginally worse than last year**
- **The most severely affected were intensive care units where around 90% had to close to new admissions – this is worse than last year**
- **Half of special care units accepted intensive care babies**

Despite the dedication and expertise of neonatal staff working hard to look after babies in the UK, capacity in the neonatal service is failing to keep up with the increased demand. One of the consequences of having a lack of specialist staffed cots is that babies and mothers are transferred far from home. While Chapter Two will look more in depth at transfers, this chapter will focus on the resources available in the neonatal unit, such as the staffing levels and the capacity of the service to look after babies.

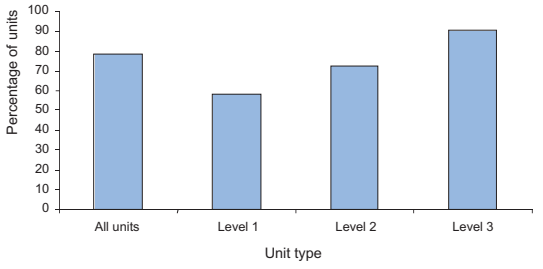
The vast majority of babies who spend time on a neonatal unit when they are born do so because they were born prematurely, which means before the 37th week of pregnancy (often referred to as gestation). A 'full term' baby will be born at 40 weeks of pregnancy (nine months). There will also be babies in the neonatal unit who were born full term but were born sick or underweight.

Neonatal units are designated a certain level. Intensive care and care for all babies, including those needing to be on a ventilator because of breathing difficulties, is available in Level 3 units. Babies born weighing less than 1000gms and under 28 weeks gestation should be cared for in Level 3 units.[3] Level 2 units will provide high dependency care for babies who need breathing support but do not need intensive care, while Level 1 units will provide special care for babies who need more medical care before they can go home. In England, care is organised into managed clinical networks which are made up of a combination of these levels, with Level 1 and 2 units clustered around one or two specialist Level 3 units.

Capacity

One of the most useful indicators to measure how busy neonatal units are is to look at whether they have been so full they have had to close to new babies and been unable to admit any more babies. Last year the research showed that 72% of units[4] had been closed to new admissions in the last six months. Depressingly, the situation has not improved but has worsened with 78% of units having to close to new admissions.

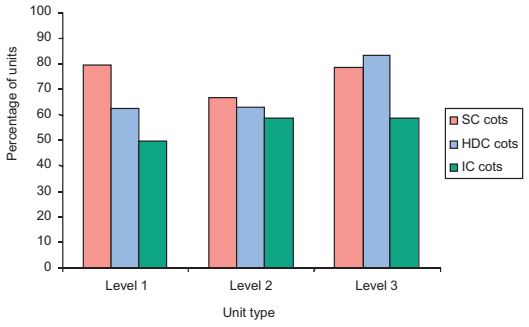
Unit closures in last six months



Almost 90% of Level 3 units with the specialist skills to look after the most vulnerable babies had to close to new admissions in last six months. These figures are worse than last year where 80% of Level 3 units had to close at least once. This clearly demonstrates that the neonatal service is in urgent need of greater capacity.

[3] *Standards for Hospitals providing Neonatal Intensive and High Dependency care* British Association of Perinatal Medicine (BAPM) 2001 p2.
[4] *NPEU report*.

Cot demands exceeding unit provision



Babies do not stop being born sick or premature because units are closed to them. They still need care. If a unit is closed, then the baby will be transferred elsewhere (for more information, see *Chapter Two: Transfers).* The research findings seem to indicate that Level 3 units are forced to close, it is the Level 1 special care units that are taking the strain. Although Level 1 units will have intensive care equipment for 'emergencies', by the very nature of their designation as Level 1 units, they should not be caring for intensive care babies because they lack the expertise. The research from NPEU shows over half of Level 1 units were caring for intensive care babies this year. It is worrying that this is an increase on last year when 40% of Level 1 units were accepting intensive care babies.

Initially, it would appear that the problem is the number of intensive care cots because it is the specialist Level 3 units that are most likely to be forced to close to new admissions. However, a closer look at the chart shows that for all units, the type of care that is most in demand is high dependency and special care cots. Therefore, what could be taking place is 'bed blocking' in intensive care. This is where intensive care units are so overwhelmed by babies needing high dependency and special care that they are forced to care for them in intensive care cots. If a baby is then born in that area who needs intensive care, they might be transferred to another unit, because their local unit is occupied by babies needing special care. The issue of clinical management of units will be further explored in *Chapter Three: Networks.*

Staffing standards

When the neonatal units were asked what the most common problem was in terms of capacity to treat patients, the overwhelming response (70%) was a lack of nursing staff.

In terms of staffing, there are several issues to consider in relation to neonatal nursing. One is the numbers of nurses working in neonatal care compared to established standards. Another is the ability of neonatal units to recruit and retain the staff with the right qualifications for their current level of funding.

It is common for adults in intensive care to receive one to one nursing. While this standard of nursing has also been recommended by medical experts[5] for babies, it has not been formally endorsed by the Government, despite references to one to one care in their own review of neonatal care in 2003.[6] This level of nursing for babies in intensive care is extremely important

- **70% of responses said nursing staff was the biggest problem in capacity**
- **69% of all units have nurse vacancies**
- **2% of units are meeting BAPM standards**

[5] *Standards for Hospitals providing Neonatal Intensive and High Dependency care* British Association of Perinatal Medicine (BAPM) 2001 p2.
[6] *Neonatal Intensive Care Review – A Strategy for Improvement* Department of Health (DH), April 2003.

- **On average, 68% of units have nursing vacancies**
- **This is most serious for Level 3 units where 73% of units have nursing vacancies**
- **Most units have on average vacancies for 2.2 Whole Time Equivalent nurses which is an improvement compared to last year**

because studies show a direct correlation between an increase in the number of babies being cared for in a neonatal unit and an increase in mortality rates.[7] These nursing standards have been endorsed by the Greater London Assembly's (GLA) Health and Social Care committee in their report *Counting the Cots – Neonatal Care Services in London* published in May 2006.[8] Their report calls for the Department of Health to increase funding so that units can meet these standards for neonatal staffing.

Only 3% of units are able to meet these nursing standards.

The research from the NPEU shows that 3% units are able to meet these nursing standards, which are designed to protect patient safety and promote the best outcome for babies.

Medical guidelines also state that neonatal units should not be working at more than 70% occupancy[9] in order to allow for peaks in demand, for example, the arrival of triplets. Given that almost all Level 3 units have had to close to new admissions, it is fair to assume that many units are working at 100% occupancy. If this nursing standard was implemented, it would massively increase the availability of staffed cots and the neonatal service should be able to keep pace with demand and reduce transfers.

Therefore, as the biggest need in neonatal care is an increase of nursing staff, it is vital that when new reforms are introduced to the National Health Service (NHS), they are applied in a way that will enable units to reach nursing standards. Neonatal intensive care will be included in Payment by Results[10] (PBR), but it would be a mistake to base the tariff on the average of current funding, given the chronic under funding of neonatal care highlighted in this report.

Many of the NHS reforms, such as the 18 week wait for operations, have been admirable but they have been designed to treat more patients more quickly. This logic cannot not apply to neonatal care, which is effectively an emergency service and should not be measured by the volume of patients treated but by improvements in outcomes for babies. Consequently, the PBR neonatal intensive care tariff should be above average funding and include a 'specialist top-up' in order to allow investment in nursing staff to reach the standard of one nurse looking after one baby in intensive care.

Staffing recruitment and retention

While job satisfaction can be high in the neonatal profession, nursing is a highly stressful occupation and this is clearly exacerbated by staff shortages. While most units reported vacancies, there is a small reduction, with an average of 2.2 Whole Time Equivalent (WTE) posts vacant in 2005 in each unit compared to 2.8 in 2004. This is clearly positive news.

[7] *Neonatal Staffing Study, Proceedings,* Neonatal Nurses Association Annual Conference, Coventry October 2000
[8] *Counting the Cots – Neonatal Care Services in London* Health and Public Services Committee, Greater London Assembly (GLA) May 2006.
[9] Op cit BAPM p4.
[10] Payment by Results is a new reform transforming the funding of the NHS away from block budgets to a system where hospital trusts will be paid for each activity they perform. Each activity or treatment will have a set price or tariff. Neonatal intensive care is set to be incorporated into the PBR system from April 2008.

Looking at the same units who were part of last year's study, our research shows that while Level 3 units have gained staff and are closer to reaching the standards, staffing levels in Level 2 particularly and Level 1 are significantly worse and are further away from meeting these important standards.

The first Baby Report, *Special care for sick babies – choice or chance?* put the estimated number of extra neonatal nurses needed at 2,700.[11] BLISS believes that unless funds are put in place to recruit more nurses, neonatal networks will be unable to put long-terms plans in place to attract and train more nurses. Commissioners need to work with networks to show how they will reach this standard over the next three years.

Examples of best practice can demonstrate that, even in expensive locations such as London, it can be possible to retain staff. The Homerton Perinatal Unit in Hackney[12] has been able to retain staff through adopting a positive approach to work/life balance and reorganising shift times to enable more flexible working. They have also invested in development and training of staff to help their future careers.

Relationships between neonatal staff and parents

Parents can spend considerable time on the unit, enduring perhaps one of the most stressful episodes of their life. Parents of sick and premature babies have frequently told BLISS that the relationship they have with the staff on the neonatal unit is very important. This means staffing levels and the availability of staff to answer queries is as important for parents as much as for the medical needs of the baby.

There is much positive news from the results of the parents surveyed on our website. High numbers of parents always felt they could sit with their baby for as long as they wanted (67%) and, importantly, always felt included in the care of their baby (64%).

Given the overall positive response by parents towards staff, it is surprising to note that over half of the parents surveyed (63%) felt that they were always or sometimes in the way. This could be partly attributed to the feelings of powerlessness that many mothers experience when having a baby in a neonatal care. It could also be due to the physical lack of space in many neonatal units, where cots are placed very close together, and so it may be difficult to accommodate parents and staff round the cot. Allowing more space for parents to sit with their babies should be a priority when any new cot space is being planned.

It is concerning that almost a quarter of all parents surveyed (23%) never had the opportunity to practise skin to skin care. Often called kangaroo care, placing the baby on to the skin of the mother and father, this type of care belongs to an approach called Developmental Care. An attempt to

[11] *Special care for sick babies - choice or chance?* BLISS July 2005. This can be accessed at www.bliss.org.uk
[12] Op cit GLA p16.

When visiting your baby did you:	Always	Sometimes	Never
Feel able to sit by your baby as long as you wanted?	67%	31%	3%
Feel you could have the people visit that you wanted?	46%	42%	12%
Have skin to skin contact with your baby?	35%	42%	23%
Sometimes feel that you were in the way?	8%	55%	37%
Find feed times flexible?	55%	36%	10%
Find that staff were aware of parents needs?	48%	48%	4%
Feel that staff were critical?	11%	38%	51%
Feel included in your baby's care?	64%	32%	5%

recognise the baby as an individual human being with emotional as well as medical needs, this type of care has shown positive benefits for both baby and parent but it has been slow to become standard practice in the UK.

However, this is a real improvement from last year, when 24% never had the opportunity to experience kangaroo care.

More positive news is that very high numbers of parents are provided with written information about the neonatal unit and the care their baby will be receiving. From our parents surveyed, 81% had received written information about the unit and 67% had been provided with written information from BLISS.

What is less clear is the availability of information in other languages or other formats, such as a DVD. The GLA reported that access to interpreting services was intermittent in London and recommended that professional interpreters should be available.

Recommendations:

- **The Department of Health should make it mandatory for the neonatal service to achieve standards of one to one nursing, for babies in intensive care.**

- **The Payment By Result tariff for neonatal intensive care must not be based on current average funding, but contain a 'specialist top–up' to allow neonatal units to invest in nursing staff and reach these appropriate standards.**

- **Commissioners must investigate how many staffed cots of different care levels are needed in their local area and make the appropriate investment.**

Chapter two
Transfers

With one in eight babies spending time in neonatal care, many people know a family member or a friend who has had a sick or premature baby. What is less known by the wider public is that large numbers of mothers and babies get transferred between hospitals very frequently. While news stories that report of mothers and babies being flown in helicopters from one end of the country to another to find a bed are thankfully rare, it is actually very common for babies and pregnant women to be transferred a significant distance away from home in order to find an intensive care cot. This chapter will examine both transfers that need to take place due to medical reasons such as babies needing surgery ('appropriate transfers') and transfers that take place because of a lack of available staffed cots ('inappropriate' transfers).

Some appropriate transfers will always need to take place. The network system of treating the sickest babies in specialised centres (Level 3 units) will require the transfer of babies from lower level units. Once a baby has received intensive care, it can be appropriate to transfer them back to their local Level 1 or 2 unit. However inappropriate transfers are those that take place not because of medical need but because of financial constraints – a lack of staffed cots.

There is a lack of centralised data on the numbers of appropriate and inappropriate transfers taking place across the UK and not all neonatal units could provide data on transfers.

Network managers in England were able to provide more information. It is very concerning that this data is not currently being collected[13] as the number of inappropriate transfers should be considered a key indicator for commissioners when planning future capacity.

Neonatal units were asked where babies went when they were transferred out of their unit. Most responses said that babies (67%) stayed within the network, some (23%) went out of the network and 10% of responses said both possibilities were likely. The units reported that there were a range of reasons for these transfers, such as a lack of staffed cots and babies needing specialist treatment available elsewhere.

It can be difficult to know which transfers are appropriate or not because some babies will need surgery that is not available in every Level 3 unit. However the Government's Review of Neonatal Services in 2003 stated that each network should be able to care for 95% of babies within its boundaries[14] (this figure allows for the transfer of babies that need surgery elsewhere).

The established clinical managed networks in England were able to provide more information on transfers. Of the 11 networks who were able to provide figures, a total of 1062 babies had been transferred out of the network, an average of 97 babies per network. Of the 10 networks who were able to provide figures, the farthest distance a baby had been transferred out of the network in the past 6 months ranged

- **Units reported that 67% of babies transferred out of the unit stayed within the network**
- **Around a quarter of babies (23%) transferred out of the unit went outside of the network**

[13] A data audit of neonatal care is currently being undertaken by the Royal College of Pediatrics and Child Health, commissioned by the Healthcare Commission.
[14] Op cit DH.

- **On average, each network transferred 109 babies out of the network in 2005**
- **Most babies travelled an average of 169 miles**
- **Over 90% of networks said transfers took place because of a lack of cots**

between 50 and 286 miles. This equates to an average farthest distance of 126 miles for these 10 networks. This is despite the aforementioned Government guidance that each network should be able to treat the vast majority of its population. When asked why these transfers were happening, the most common response was a lack of cots. This shows that most transfers taking place are inappropriate transfers. Babies are being moved around the country primarily because of financial rather than clinical reasons.

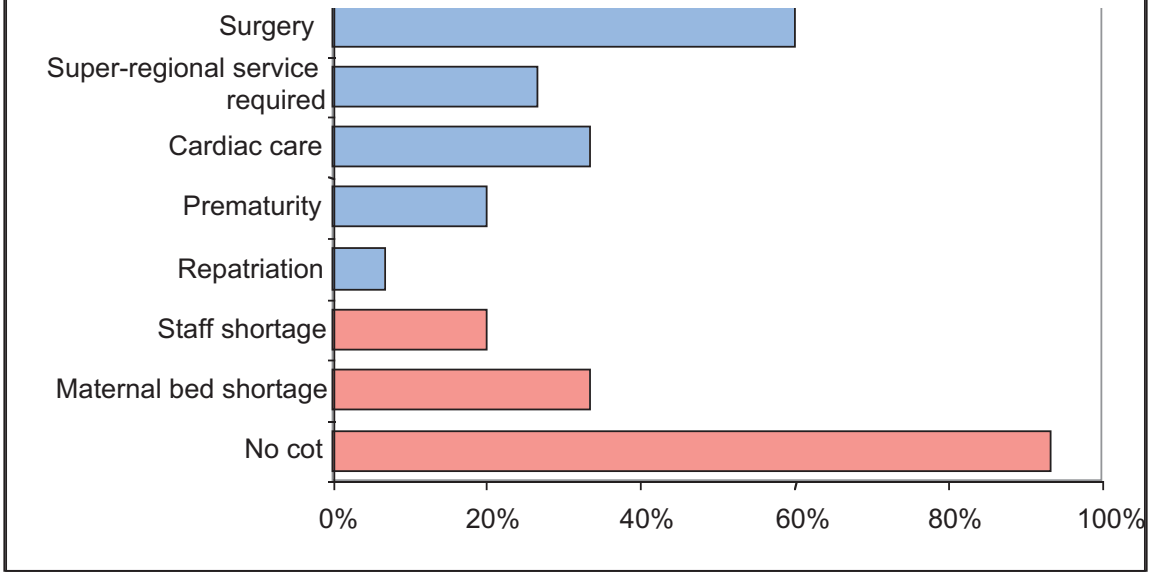
If babies are being transferred out from somewhere, they are being received by someone else. The NPEU asked units and networks for the most common reasons why babies are transferred into them. Again a common response was a lack of capacity. More positively, units did respond by saying that most transfers into the unit came from other sister units within the network (70%) and, alongside capacity, the most common reason was babies returning back to their local unit after specialist care elsewhere.

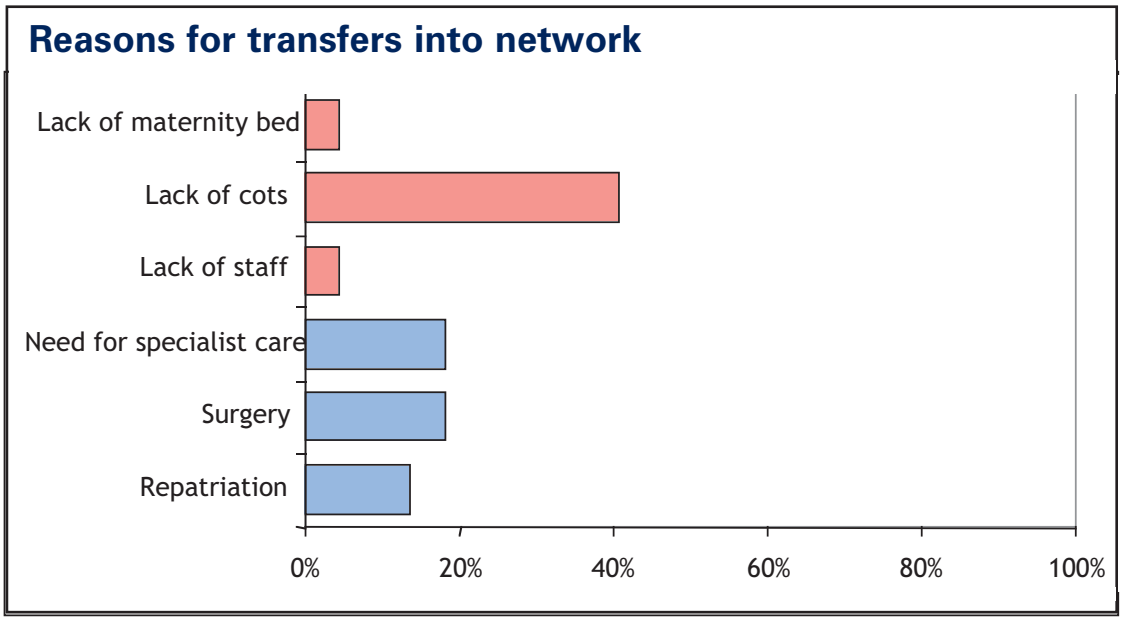
"I was transferred in labour from my local hospital to one two hours away, then two days later the intensive care cot had gone, so I was transferred in full labour 20 minutes down the road to the next hospital with an intensive care cot."

Transport arrangements

Comments made by parents about transfers highlight how stressful transfers can be and how transport arrangements can sometimes be unpredictable. While Scotland has an effective neonatal transport service, comments from network managers

Reasons for transfers out of network





and unit staff, especially in England, shows wide variation in transport arrangements. For example, while ten networks reported having a network wide service, only four networks have a 24 hour hotline and six networks have a daytime only service. Eight networks reported that they had an 'ad hoc' transport service.

The safe and effective transport of mothers and babies is an integral part of running a clinically managed neonatal network. Therefore it is imperative to increase funding to ensure that all networks have the capacity to run a 24 hour staffed neonatal transport team.

Anecdotal evidence provided shows transport teams can be vulnerable to cuts. One way to protect monies for neonatal transfer could be to introduce a separate neonatal transfer tariff as part of Payment by Results. It may prove more useful for networks to collaborate to provide transport arrangements that cover a region rather than one network. For example, the London Emergency Bed Service (EBS) provides the Neonatal Transfer Service (NTS) which covers London, Surrey, Sussex and Kent. It employs a team to check on cot availability and a team of medical and nursing staff to undertake the transfers.

"There were no intensive care cots available in my home town. I was transferred out before the baby was born, then transferred back when my baby was seven days old."

At the time of writing, the Department of Health (DH) was in the process of introducing a national online cot bureau incorporating the existing bureaus. This is certainly welcome as it will save clinicians and nurses time in finding available staffed cots. However, it will mean that staff will have to spend time away from patients updating the online system and this work will need to be

- **A third of mothers surveyed were transferred before or during labour**
- **15% of parents said they did not expect the transfer of their baby**
- **20% of parents expected their baby to be transferred but this did not happen**

covered. Disappointingly, the DH proposals do not currently include any resources for extra dedicated transport teams.

Transfers of mothers

The NPEU survey did not cover maternal bed availability and therefore we do not have hospital data on the transfer of expectant mothers. However we do have information from women who responded to our online parents' survey. A third of these (33%) were transferred just before or during labour. The results of the survey point to a number of reasons why these transfers take place: concern over the health of the baby and or the mother, likelihood that the baby would need specialist care not available at that hospital, or insufficient intensive care cots for the expected baby.

While our parents surveyed included a large proportion of parents of the smallest and sickest babies, this is still a significant number of women needing to be transferred either in labour or who are about to go into labour. This is clearly distressing for the mother but it is actually safer for the health of the baby if it is the mother who is transferred rather than the baby once it has been born.

However, this raises the question whether mothers are being given sufficient information to help their choice in booking their hospital for their delivery. This will be further explored in *Chapter Three: Networks.*

Transfers of babies

The survey reveals a large degree of uncertainty for families regarding transfers. As with the general public, some parents (15%) were completely unaware before their baby was born that their baby would be transferred. Other parents (20%) were told they were likely to be transferred but this did not actually happen. This ambiguity and lack of information about the likelihood of a transfer could be related to the limited and fluctuating capacity of the neonatal service.

"I had absolutely no idea that there was a possibility that my babies would be transferred. This was never explained to me at any stage during my pregnancy or labour. We were transferred 40 miles away."

Transfers are clearly very distressing for parents. It can be even more difficult for mothers who may be unwell following delivery, having had a caesarean or unable to travel after.

Parents can also find it very costly visiting their baby in a neonatal unit. This is of course exacerbated when a baby has been transferred far from home and even more frustrating

if this transfer has been for non-clinical reasons. Lower socio-income group families are more likely to have a low birth weight[15] or premature baby and therefore the poorest families may be suffering the most financially.

Our online survey provided an opportunity for parents to give advice to other parents and much of this focused on financial assistance, because parents were unable to find this information easily.

"My baby had to wait for a team to come over by ambulance and then assess him. During this time, his intensive care cot was taken in the transfer hospital so he had to go to another unit further away."

- **14% of parents travelled more than 30 miles a day to see their baby**
- **The average daily cost of travel was £6.63 a day**
- **10% of parents had to pay more than £20 per day for travel.**

Recommendations:

- **The Department of Health should introduce a separate Payment by Results tariff for neonatal transport.**
- **Regional transport teams should be established covering at least three networks (Strategic Health Authority wide basis for England and country wide for Scotland, Wales and Northern Ireland).**
- **Information on financial help available needs to be made more accessible and actively distributed to parents when in the neonatal unit.**

[15] *Social inequalities in low birthweight in England and Wales: trends and implications for future and implications for future population health.* K Moser, L Li, C Power, J. Epidemiol Community Health 2003

Chapter Three
Networks

- **60% of mothers only found out that their baby would need neonatal care when in labour or immediately after birth**
- **13% of all parents knew about neonatal networks**
- **36% of mothers were told during pregnancy their baby might need neonatal care**

The chief recommendation of the Government's 2003 Review of Neonatal Services[16] in England was for neonatal care to be reorganised into a series of clinically managed networks. Healthcare networks are "linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality, clinically effective services …. ".[17] This chapter will study the impact of neonatal networks in England on the quality of care for babies and their affect on parents.

There are two main advantages of this network arrangement. Firstly, the centralisation of specialist care for the sickest babies means that medical and nursing staff develop and maintain their expertise. Families are reassured that those caring for their baby are experts and are continually adding to their experience and updating their skills. The second advantage is that networks can pool resources from different hospitals which can save money, especially the costs of medical staff who will be concentrated in level three units.

Networks and parents

While 'clinical managed networks' have been introduced in other healthcare areas (such as cancer and cardiac services[18]) and have become a standard component of current healthcare policy, it is highly concerning that only a small number of parents (13%) knew that neonatal care was organised into networks. Even taking into account people who responded to our survey that may have been in Scotland, Wales or Northern Ireland (where there are no formal networks), this is a very low figure.

Labour's 2005 manifesto promises mothers a choice of pain relief during birth and a choice over where they want to have their baby.[19] In order to have the full range of information when making their choice and to prepare mothers for what might happen to them if their baby needs neonatal care, mothers need to be informed of what neonatal network they are in when they book their hospital for delivery. This is especially important for 'high risk' mothers who have been identified as possibly needing neonatal care. This would also highlight a need for close cooperation between maternity and neonatal networks and between commissioners of these services.

The need to provide pregnant women with more information about neonatal networks is further reinforced by the findings of our survey shows that the majority of women were unprepared for their experience of neonatal care. Over a third of mothers surveyed (36%) were told during their pregnancy that it was highly likely that their baby would need to spend time in neonatal care. However, for the vast majority of women (60%), it came as a complete surprise that their baby would need to be admitted to neonatal care and they only found out during labour or immediately after birth.

[16] Quotes 2003 review.
[17] *The National Service Framework for Children, Young People and Maternity Services,* Department of Health and Department for Education and Skills, September 2004.
[18] *A Guide to Promote a Shared Understanding of the Benefits of Local Managed Networks*, Department of Health and Department for Education and Skills, June 2005.
[19] "By 2009 women will have a choice over where and how they have their baby and what pan relief to use" Labour manifesto, 2005.

Networks – the story so far

While units in Scotland frequently collaborate, there is no formal neonatal network structure. The same is true for Northern Ireland, and there are plans in progress to create neonatal networks in Wales.

The NPEU research shows that there are now 22 formal networks in England. All active networks have managers in place, although over half of these (55%) are part-time. While 41% of networks do not have a lead nurse for the network, all networks have a lead clinician in post.

Positive results

Our survey of both network managers and units shows that networks have played an overwhelmingly positive contribution in building better relationships between units, enabling collaboration and promoting best practice. Network managers reported that networks had enabled cooperation in resource and capacity planning. Close working between units had also led to widespread shared education and training programmes, the development of guidelines and standards, and the compiling of data. This is important because this collaborative working should bring particular benefits in standardising care amongst units and promoting best practice.

Networks have also proved useful in gaining some extra funding for nursing and medical staff. A quarter of units reported that there had been changes to nurse staffing and 54% of units reported changes to medical staffing as a consequence of the network. Examples included the introduction of new Advanced Neonatal Nurses Practitioner (ANNP) roles, and rota changes to enable more flexibility and cover.

The bulk of the work is still to be done

However, despite the useful collaboration between staff in different units, networks are not clinically managing the flow of patients between units. The evidence in *Chapter One: Neonatal care resources* demonstrates that, not withstanding the huge problem of capacity in the neonatal service, which is beyond the control of network managers, there is also an issue of the management of cots. Are the right types of cots available in the right places in the right volumes? The capacity figures suggest that high dependency and special care are most in demand but, compared to last year, the number of Level 1 units who can provide this care has gone down. Four networks reported that they actually have no Level 1 units at all.

The biggest hurdle facing the development of the networks was the designation of the units into different levels and setting guidelines as to which patients they should treat. This was clearly a difficult process and the inevitable 'downgrading' of some units was the biggest concern for network managers. In many cases, despite the running of networks for two to three

- **Two networks reported having no lead Level 3 centre agree**
- **One network reported having three units at 'Level 2.5'**
- **Six networks reported having 'Level 4' units**

- **Around 25% of networks reported having extra funding for nursing posts**
- **All networks have appointed clinical leads**
- **55% of network managers are part-time**

years, many of the difficult decisions have yet to be taken on designation. Some explanation for this might be the lack of central government guidance and decision making. It is also interesting to note that network leadership is dominated by clinicians who have clear vested interests in the designation of units.

It is likely that the reconfigurations of Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs) will further complicate the running of networks, as many network board positions are currently occupied by PCT representatives who may now change. While this time of change may present challenges to networks, it could also present an opportunity. In particular, it represents a chance to enhance the role of SHAs in performance managing the commissioning of neonatal care.

Professor Sir David Carter's report *Review of Commissioning Arrangements for Specialised Services*[20] published in May 2006 highlight ways that commissioning arrangements can be improved for specialised services and the report outlines clear roles for SHAs and PCTs. BLISS endorses this report and looks forward to its implementation and strengthening of commissioning arrangements, to be overseen by the Healthcare Commission.

Recommendations:

- **The Department of Health should commission research to evaluate the effectiveness of neonatal networks. This report should be shared with Scotland, Wales and Northern Ireland to influence their creation of formal neonatal networks.**
- **The recommendations of Professor Sir David Carter's report *Review of Commissioning Arrangements for Specialised Services* should be implemented immediately and monitored and evaluated by the Healthcare Commission.**
- **Network boards should work with commissioners to ensure there are the right types of cots available in the right place in the right volumes.**

[20] *Review of Commissioning Arrangements in Specialised Services* Professor Sir David Carter, May 2006.

Chapter Four

Mortality rates

- **Two out of every three deaths before the first birthday are attributed to prematurity**
- **Babies born to teenage mothers are 60% more likely to die**
- **Around 10% of infant deaths will be to single mothers**

Out of all babies who died before their first birthday, two thirds died because they were born premature.[21] Mortality rates measure the number of babies dying and are commonly used as indicators to show how effective the UK health service is in caring for mothers and babies. Mortality rates can also be useful in comparing the expectations for babies born in different areas or to parents with different backgrounds. The first year of life is arguably the most important in terms of determining a child's future.[22]

Overall, the number of babies dying before their first birthday has shown a small decline in the last year. Despite this good news, a closer look at the statistics shows that this decline is benefiting certain sections of the public more than others. It is important to examine the inequalities at birth as these can have a significant impact on the outcomes for these babies.[23]

England

As the table on page 22 shows, the overall number of babies dying is going down slowly. However, the Government set a target in 2004 of "starting with children under one year, by 2010 to reduce the gap in mortality by at least 10% between 'routine and manual' groups and the population as a whole".[24] Despite the welcome ambition of this target, a Government report in August 2005 said that reaching this target remains "extremely challenging".[25] This is because while the overall number of babies dying has gone down, the figures show that babies born to families were the father has a 'routine and manual' job have an infant mortality rate 69% higher than families were the father is employed in 'managerial and professional' work.[26]

There are clear links between social deprivation and the likelihood of having a low birthweight baby and a baby that does not survive. When looking at mothers, one of the groups most at risk is teenage mothers who have a 60% increased risk[27] of having a baby die before their first birthday (infant mortality rate of 7.7 per 1,000 live births).[28] Another area of concern is the high number of babies dying to 'sole registrations', that is single mothers. Around 10% of infant deaths will be attributed to this group.[29]

Similarly with the 'social' divide, there are differences in outcomes for babies with regards to ethnic background. Babies of mothers born in Pakistan, the Caribbean and parts of Africa had particularly high infant mortality rates (between 8.5 and 8.8).[30]

There are differences again in outcomes with regards to geographical area. BLISS undertook a study into the regional variations in infant mortality in March 2006. An answer to a parliamentary question revealed infant

[21] *Childhood, infant and perinatal mortality,* series DH 3 no 36 Office of National Statistics.
[22] An equal start — Improving support during pregnancy and the first twelve months, Lisa Harker, Liz Kendall IPPR, April 2003.
[23] *Narrowing the Gap*, The Fabian Commission on Life Changes and Child Poverty, April 2006.
[24] 2004 *Spending Review PSAs*, Chapter Three Department of Health, HM Treasury, July 2004.
[26] *Tackling Health Inequalities: Status Report on the Programme for Action* Department of Health, August 2005.
[27] ibid.
[28] ibid.
[29] *Infant and perinatal mortality by social and biological factors*, 2004 Health Statistics Quarterly.
[30] Winter 2005, National Statistics.

- **Babies of mothers born in Pakistan, the Caribbean and parts of Africa had particularly high infant mortality rates**
- **Babies are eight times more likely to die in central Birmingham than in Surrey**
- **The top three worst places for infant mortality in England have a rate that is double the national average**

Worst area for infant mortality	
Area	**Rate**
1. Central Birmingham	12.4
2. North Kirklees	11.2
3. Central Bradford	10.4
4. East Birmingham	9.2
5. Central Manchester	8.6

Best area for infant mortality	
Area	**Rate**
1. East Elmbridge and mid–Surrey	1.5
2. East Devon	1.8
3. Central Suffolk	1.9
4. South Somerset	2.2
5. Chiltern and South Bucks	2.2

mortality rate by Primary Care Trusts (PCTs). Taking a three year average (2002 to 2004) and making an adjustment in order to account for the areas of very low birth rate, we published a league table showing the 'worst' and 'best' areas for infant mortality in England.

The huge variations are shocking as Central Birmingham (Heart of Birmingham PCT) has eight times the number of babies dying than the lowest rate in the country, which is in mid-Surrey. Generally, the figures show worse outcomes for babies born in large cities in the North West and Midlands compared to the better areas concentrated in the suburban South.

Scotland

At the time of writing, detailed local and regional data was not available for Wales and Northern Ireland. However, there is information available on Scotland[31] regarding geographical area (parliamentary constituency) and infant mortality. This has not been adjusted in order to take account of areas with low birth rate. The tables on page 23 show a similar pattern to England. There are some huge variations in infant mortality across Scotland, with the worst area, Greenock and Inverclyde, having a rate that is seven times worse than the best area, Caithness, Sutherland and Easter Ross.

While we welcome the overall decline of mortality rates, the serious inequalities between different geographical areas and social groups give grave cause for concern and represent a failure of health care policy. As indicated earlier in the report, the number of premature babies is rising. It is imperative that neonatal services keep up with the demand. Infant mortality is a wider

[31] Op cit BLISS 2005.
[32] This is infant mortality in Scotland based on three year average death rate between 2002 to 2004 by parliamentary constituency. This information was contained within a Scottish parliamentary answer given on 15 May 2006 in response to a question tabled by Shona Robison (SNP, Dundee East).

Worst area for infant mortality	
Area	**Rate**
1. Greenock and Inverclyde	10.8
2. Shetland	10.1
3. Glasgow Springburn	9.7
4. Clydebank and Milngavie	9.5
5. Paisley	8.8

Best area for infant mortality	
Area	**Rate**
1. Caithness, Sutherland and Easter Ross	1.5
2. Inverness East, Nairn and Lochaber	1.9
3. Dumfries	2.1
4. Glasgow Rutherglen	2.3
5. Gordon	2.4

issue than just neonatal services as it encompasses public health the proven links between certain risk factors during pregnancy, such as smoking.[33] The significant inequalities raise questions as to how effective current health services are in providing access to healthcare and support during pregnancy for all women.

Central government must make reducing the inequalities in outcomes for babies a priority. This can be shown by renewing the existing infant mortality target in the 2007 Comprehensive Spending Review and providing extra funds to enable real progress in reaching this target. However, this issue must equally be tackled on a local level with targeted interventions for different groups. It is local Primary Care Trusts who should have a lead role in reducing infant mortality in their area. Commissioning of maternity and neonatal services should focus more on outcomes such as reducing inequalities in the expectations of outcomes for babies rather than cost and volume.

Recommendations:

- **The Government should commit to a new Public Service Agreement (PSA) target to reduce inequalities in infant mortality as part of the 2007 Comprehensive Spending Review.**

- **Primary Care Trusts should design targeted public health interventions to help to minimise the risk factors for having a premature or sick baby.**

- **All political parties should pledge to reduce inequalities in infant mortality and to provide more targeted support to vulnerable pregnant women in their next election manifestoes.**

[33] Sure Start http://www.surestart.gov.uk/surestartservices/healthrelated/healthandfamilysupport/smoking/

Conclusion

The evidence from the NPEU's preliminary results contained within our report show a neonatal service in crisis. Neonatal units are under so much pressure, because of a lack of staffed cots, that over 90% of intensive care units have had to close their doors. Almost every third day, a baby is transferred out of their network, around 126 miles away, and the majority of these transfers are due to a lack of available staffed cots. Most concerning is that the situation has worsened compared to last year, with units under so much pressure that half of all special care units accepted intensive care babies. This is an issue of patient safety and it is unacceptable that a life saving service is unable to provide the appropriate level of care to vulnerable babies because of financial constraints.

The most pressing need is for central government to commit to the recommended nursing standards of one nurse looking after one baby in intensive care. The main problem in neonatal care is a lack of staffed cots and therefore it is vital to implement this standard to boost nursing numbers. It can be heartbreaking for parents to discover that their baby needs intensive care and extremely frustrating to see empty cots in their local unit go unused because of a lack of staff, forcing them to be transferred elsewhere, far from home.

The Department of Health has a responsibility to ensure that new reforms in the NHS will be introduced in a way that does not harm a particular healthcare area. Clearly the existing funding and commissioning system has not served the neonatal service well on the evidence of current problems. Therefore reform is welcome. However reforms must seek to improve the outcomes of babies. BLISS would like to see a neonatal intensive care tariff within the Payment by Results system that will include a 'specialist top-up' to enable networks to invest in nursing staff to reach the recommended levels. Equally it is important to ensure that commissioning arrangements are revised and BLISS supports the recommendation of Professor Sir David Carter's report on this matter.

The policy to reorganise neonatal care into networks has proved useful in terms of greater collaboration and working between units. This has brought particular benefits to the training of staff and the development of common standards. However, constrained by a lack of capacity, neonatal networks have been less successful in clinically managing the flow of babies between different types of care. This has also been hampered by delays in designation of units. The Department of Health should examine the success and weakness of neonatal networks and provide guidance for their future development.

While it is very welcome news that infant mortality rates are going down, the challenge now for public health professionals, maternity and neonatal services is to reduce the inequalities in different parts of the country and between different groups.

Summary of recommendations

Neonatal care resources

- The Department of Health should make it mandatory for the neonatal service to achieve standards of one to one nursing, for babies in intensive care.

- The Payment by Result tariff for neonatal intensive care must not be based on current average funding, but contain a 'specialist top–up' to allow neonatal units to invest in nursing staff and reach these appropriate standards.

- Commissioners must investigate how many staffed cots of different care levels are needed in their local area and make the appropriate investment to provide them.

Transfers

- The Department of Health should introduce a separate Payment by Results tariff for neonatal transport.

- Regional transport teams should be established covering at least three networks (Strategic Health Authority wide basis for England, country wide for Scotland, Wales and Northern Ireland).

- Information on financial help available needs to be made more accessible and actively distributed to parents when in the neonatal unit.

Networks

- The Department of Health should commission research to evaluate the effectiveness of neonatal networks. This report should be shared with Scotland, Wales and Northern Ireland to influence their creation of formal neonatal networks.

- The recommendations of Professor Sir David Carter's report *Review of Commissioning Arrangements for Specialised Services* should be implemented immediately and monitored and evaluated by the Healthcare Commission.

- Network boards should work with commissioners to ensure there are the right types of cots available in the right place in the right volumes.

Mortality

- The Government should commit to a new Public Service Agreement (PSA) target to reduce inequalities in infant mortality as part of the 2007 Comprehensive Spending Review.

- Primary Care Trusts should design targeted public health interventions to help to minimise the risk factors for having a premature or sick baby.

- All political parties should pledge to reduce inequalities in infant mortality and to provide more targeted support to vulnerable pregnant women in their next election manifestoes.

References

[1] Editorial: *Why should preterm births be rising?* BMJ Volume 332, pp 924 – 5, 22 April 2006.

[2] *Special care for sick babies – choice or chance?* BLISS July 2005. This can be accessed at www.bliss.org.uk and the NPEU research which formed the basis of this report can be accessed at www.npeu.org.uk

[3] *Standards for Hospitals providing Neonatal Intensive and High Dependency care* British Association of Perinatal Medicine (BAPM) 2001 p2.

[4] *NPEU report.*

[5] *Standards for Hospitals providing Neonatal Intensive and High Dependency care* British Association of Perinatal Medicine (BAPM) 2001 p2.

[6] *Neonatal Intensive care Review - A Strategy for Improvement* Department of Health (DH), April 2003.

[7] *Neonatal Staffing Study, Proceedings,* Neonatal Nurses Association Annual Conference, Coventry October 2000.

[8] *Counting the Cots – Neonatal Care Services in London* Health and Public Services Committee, Greater London Assembly (GLA), May 2006.

[9] Op cit BAPM p4.

[10] Payment by Results is a new reform transforming the funding of the NHS away from block budgets to a system where hospital trusts will be paid for each activity they perform. Each activity or treatment will have a set price or tariff. Neonatal intensive care is set to be incorporated into the PBR system from April 2008.

[11] *Special care for sick babies – choice or chance?* BLISS July 2005. This can be accessed at www.bliss.org.uk and the NPEU research which formed the basis of this report can be accessed at www.npeu.org.uk

[12] Op cit GLA p16.

[13] A data audit of neonatal care is currently being undertaken by the Royal College of Pediatrics and Child Health, commissioned by the Healthcare Commission.

[14] Op cit DH.

[15] Social inequalities in low birthweight in England and Wales: trends and implications for future and implications for future population health. K Moser, L Li, C Power, J. Epidemiol Community Health 2003.

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[30] Winter 2005, National Statistics.

[31] Op cit BLISS 2005.

[32] This is infant mortality in Scotland based on three year average death rate between 2002 to 2004 by parliamentary constituency. This information was contained within a Scottish parliamentary answer given on 15 May 2006 in response to a question tabled by Shona Robison (SNP, Dundee East).

[33] Sure Start: http://www.surestart.gov.uk/surestartservices/healthrelated/healthandfamilysupport/smoking/

Appendix A - BLISS Baby Charter

The BLISS Baby Charter for special care babies

Every baby in the United Kingdom regardless of race, religion or culture has the right to benefit from:

- the same respect and dignity as adults
- the decisions affecting their care being made in their best interests
- the same level of specialist care as children and adults
- the same chances of survival as babies born in similar countries and circumstances
- the information and support needed by parents to help them care for their baby and achieve the best quality of life possible
- the opportunity to have their mother's breast milk where appropriate
- the necessary support and care after going home

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