



The chance of a lifetime?

Bliss Baby Report 2010

Bliss

for babies born too soon,
too small, too sick



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Foreword

Last year Bliss celebrated its 30th birthday. We marked the occasion with a report looking back at the major advances that have been made in the care of babies born too soon, too small and too sick over the last three decades.

At the launch of our report, in the House of Lords in November 2009, the Parliamentary Under-Secretary of State for Health also launched the *Toolkit for High Quality Neonatal Services*ⁱ (*Toolkit*). The *Toolkit* sets out an ambitious vision for neonatal services in England. In its eight principles of care, it spells out how services should be organised and delivered to provide the best possible care to babies and their families.

In the year since its launch, health professionals and managers working in neonatal care have started to take action to ensure their own services meet the standards set out in the *Toolkit*. There have also been some welcome policy developments, including the development of the National Institute for Health and Clinical Excellence's (NICE) *Quality Standards for Specialist Neonatal Care*. We also welcome the establishment a group of experts, including Bliss, to advise senior NHS officials in the National Quality Board about the barriers to further improvement in neonatal services and how these can be overcome. At the frontline there have been welcome local improvements, with a number of transport services increasing their hours and coverage.

However, as this report sets out, neonatal services still face major challenges. Bliss has been reporting about services being overstretched and understaffed since our first *Baby Report* in 2005. While it is clear that progress has been made in some important areas, many of the same problems remain: a shortage of neonatal nurses, units working over capacity, and a lack of support for families.

The *Toolkit* and new *Quality Standards*, together with proposals recently announced by the Coalition Government to set up maternity networks, offer the chance of a lifetime to transform care for vulnerable babies. Action is needed now to make the most of this opportunity.



Andy Cole
Chief Executive
Bliss



IT'S
A BOY



Key findings

Neonatal nurse shortages

- Less than a third of neonatal units have enough nurses in post to meet the minimum standards set by government and the NHS. We estimate an extra 1,150 nurses are needed across all units in England to meet these standards.
- Less than a quarter of neonatal intensive care units meet the minimum nursing standards. 700 more nurses are needed to fill the shortfall in neonatal intensive care units alone.
- Almost 80 per cent of the additional nurse posts needed for all units to meet the standards are not funded at present. Vacancies only account for around 20 per cent of the gaps in units not meeting the standards.
- Only around half of units meet the standard for the proportion of nurses needed with a specialist qualification in neonatal care.
- Only around half of units have nurses providing community outreach to babies, once they have left hospital.

Medical shortages

- Six neonatal units have consultant grade doctor vacancies that they have been unable to fill for more than three months.
- Units in some areas are facing major problems recruiting junior and middle grade doctors.

Allied health professionals and counselling

- In a snap shot of services taken in June 2010, only half of units said they had provided counselling for families.
- Two thirds of units provided physiotherapy and specialist nutritional support to babies in this period, while only half provided speech and language therapy, and only one in four provided occupational therapy support for babies.

Closures, occupancy levels and transfers

- Three quarters of units had to close to new admissions at some point in 2009. Some of the most common reasons for this were shortages of nurses and doctors.
- While units should be running at no more than 80 per cent occupancy, eight out of ten units reported running at 100 per cent occupancy or more at some point in 2009. Neonatal intensive care units are running at an average of over 94 per cent occupancy. Occupancy in some units reached over 200 per cent for extended periods.
- 90 per cent of transfers made by transport teams, from hospitals outside of their networks into their own units, were due to capacity issues in outside networks.

Parent accommodation

- Almost all hospitals have some overnight accommodation close to the unit. However, to meet the standard set out in the *Toolkit*, at least 250 more rooms for parents to stay overnight are needed.

Financial difficulties

- Parents of babies admitted to neonatal care face additional costs totalling £2,800 on average. This additional outlay relates to the costs involved in visiting their babies and time away from work.

Introduction

Approximately 70,000 babies were admitted to neonatal care in England in 2009. This is one in nine of all babies born in England last yearⁱⁱ.

Categories of care

Neonatal care includes three categories of care. These are:

- **Special care** – the least intensive level of care and most common. This includes care such as monitoring of a baby's breathing and heart rate, provision of ultra violet light for jaundice, being fed by tube or supplied with extra oxygen.
- **High dependency care** – this level of care is for babies weighing less than 1,000g, or who are receiving help with breathing via continuous positive airway pressure or intravenous feeding but who do not require intensive care.
- **Intensive care** – highly specialised care for the most seriously ill babies who will often be on a ventilator or need constant care to keep them alive.

Levels of neonatal units

These three categories of care are delivered across three levels of neonatal units. These levels are:

- **Special care baby units** – provide special care for their own populations. May in some areas, subject to local agreement, provide some high dependency care to babies.
- **Local neonatal units** – provide all categories of neonatal care, including short term intensive care, however they will transfer babies requiring complex or longer-term neonatal care to neonatal intensive care units.
- **Neonatal intensive care units** – provide the most specialist care for the sickest babies across their network, also provide the whole range of neonatal care for their local population.

Neonatal services are organised into 23 neonatal networks across England. These networks co-ordinate the care of babies across a group of provider organisations (the neonatal units) to ensure that babies receive the care they need, as close to home as possible. The units within each network provide a range of levels of neonatal care.

In July 2010 Bliss sent a survey to all 177 units in England. We received responses from 116 units, an overall response rate of 66 per cent. We also conducted a survey of neonatal transport services and of parents of babies admitted to neonatal care. The findings of this report are based on these responses.

There were 47,865 admissions to the 109 units who responded to our question about admission figures. Scaled up to all 177 units in England, we estimate that there were a total of 70,685 admissions in 2009.

In November 2009, the *Toolkit for High Quality Neonatal Services* was published by the Department of Health and NHS, outlining a comprehensive set of standards for neonatal services covering the staffing of units, how surgical services should be delivered, how units should be organised and governed, and the facilities and support that should be available to families.

This report looks at how services are performing in relation to these standards, setting out where further improvements are needed in the care of babies born premature and sick to meet these standards.

Staffing and capacity issues in neonatal care

Nurses form the backbone of our neonatal services. From non-registered nursing assistants to those highly trained with specialist qualifications in neonatal intensive care, nurses of all levels provide the vast majority of hands-on care to babies born too soon, too small and too sick.

Working alongside the nursing staff are doctors and a wide range of other professionals providing services such as physiotherapy, feeding and nutritional support to babies, in addition to care, such as counselling, for family members.

Neonatal nurse levels

The *Toolkit for High Quality Neonatal Services* set out minimum standards (see below) for the number of nurses needed to look after babies within each level of care.

Staffing of neonatal services

- **Special care:** a minimum of one registered nurse/midwife to four babies at all times (or non-registered nurse working under the supervision of a registered nurse).
- **High dependency care:** a minimum of one specialist neonatal nurse/midwife to two babies at all times (or nurses in specialist training working under the supervision of a specialist nurse).
- **Intensive care:** a minimum of 1:1 nursing is provided at all times by a specialist neonatal nurse/midwife (or a nurse in training working under the supervision of a specialist nurse).

Toolkit for High Quality Neonatal Services, Department of Health & NHS (2009)

The above standards outline the ratio of nurses to babies required for direct hands-on care. However the *Toolkit* also sets out that all units should have a nursing coordinator on every shift in addition to those providing hands-on care.

107 neonatal units provided information about the number of nurses they had in post. These units had a combined total of 4,254 whole time equivalent* nurses responsible for providing direct care to babies. Scaled up for all 177 units in England, we can assume that there are a total of 6,600 nurses providing this direct care to babies across the country.

Of the 96 units that provided information about their nursing staff and cot occupancy levels, only 29 (30 per cent) have enough nurses in post to meet the minimum standards set out in the *Toolkit*.

There is a shortfall of almost 970 nurses in the 67/96 units not meeting the nursing standards. Assuming staffing levels in these 96 units are representative of the 177 units across England, there is a shortfall of approximately 1,150 nurses to provide direct hands-on care to babies across England. This indicates a small improvement on the findings of our research from 2008, where we found that an extra 1,215 nurses were needed in Englandⁱⁱⁱ.

Units not meeting *Toolkit* standards on nurse staffing

| | Number of units not meeting standard (lack of funded posts) | Number of units not meeting standard (lack of funded posts and vacancies) | Nurses in post (direct care givers) | Nurse shortfall (lack of funded posts) | Nurse shortfall (lack of funded posts and vacancies) |
|--|--|--|--|---|---|
| Special care baby units (17 units) | 9 | 10 | 340 | 30 | 60 |
| Local neonatal units (41 units) | 24 | 28 | 1250 | 155 | 210 |
| Neonatal intensive care units (38 units) | 23 | 29 | 2665 | 585 | 700 |
| Total (96) | 56 | 67 | 4255 | 770 | 970 |

*The term 'whole time equivalent' refers to number of full-time filled posts. All staffing figures in this report relate to whole time equivalent posts.

However the *Toolkit* standards on nursing levels in neonatal care are not new, they mirror clinical guidelines set out by the British Association of Perinatal Medicine (BAPM) in 1996, 2001 and again in 2010^{iv}. Previous reports by Bliss^v and by organisations such as BAPM^{vi} have repeatedly highlighted the scale of the challenge in meeting the shortfall in neonatal nurses across the country.

There is a particular shortage of nurses working in the more specialist centres. Only nine of the 38 neonatal intensive care units that responded to our survey have enough nurses in post to meet the minimum standards on nursing. 700 more nurses are needed to fill the gaps in these neonatal intensive care units alone.

These findings mirror those in our 2008 report, *Baby steps to better care*,^{vii} which highlighted particular pressures faced by intensive care units. Following this report, Bliss launched its 'One to one nursing' campaign aimed at raising the profile of these issues with the public and policy makers. A significant step forward came with the endorsement of the BAPM staffing standards in the *Toolkit*.

In order to fully close the gap between the current nursing numbers and the number that is required to meet minimum standards, it is necessary to understand the two main factors in the shortfall of nurses working in neonatal care: insufficient funding for neonatal nurse posts and problems recruiting and retaining nurses in the speciality.



Shortage of funding for nurse posts

Even if all the vacancies were filled, our survey showed that many units would still fail to meet the nursing standards set out in the *Toolkit*. We compared the information that units provided about how many nurse posts they received funding for with our calculation of how many nurses each unit needed to meet the *Toolkit* standard. We found that the number of funded nurse posts in three fifths of units (56/96) is set at a level that is insufficient to meet the *Toolkit*'s nursing standard.

The lack of sufficient funded nurse posts accounts for 79 per cent (770/970) of the total shortfall in nurses, in units not meeting the *Toolkit* standard.

Neonatal nurse vacancies

"Due to nursing vacancies we have only been able to staff (three-quarters of the cots we are designated to provide) for the last two to three years and even to achieve this we frequently use bank nurses (our own nursing staff working extra shifts up to 48 hours per week)." (Neonatologist)

More than three-quarters of units (76 per cent), reported vacancies for nurses providing hands-on care in the hospital. These vacancies came to a combined total of 395 whole time equivalent unfilled nurse posts. Scaled up for all units in England, we can estimate that there are around 620 vacancies for nurses providing direct care to babies.

A number of units also reported particular problems filling vacancies for more experienced nurses and those with specialist training in neonatal care.

"(It is) very difficult to recruit experienced neonatal nurses Band 6 and above, (which is) not helped by lack of co-ordinated neonatal nurse training strategy from local universities... and a decade of gradual reduction in training money available for neonatal nursing." (Senior nurse)

Specialist nurses

The *Toolkit* outlines that 70 per cent of the registered nursing and midwifery workforce in each unit should have a post-registration qualification in specialised neonatal care. Just over half of the units (55 per cent) meet this standard.

Units meeting *Toolkit* standards on percentage of nurses with specialist qualification

| Responses | Number of units meeting standard for nurses with specialist neonatal qualification |
|--|--|
| Special care baby units (21 units) | 8 |
| Local neonatal units (40 units) | 24 |
| Neonatal intensive care units (38 units) | 22 |
| Total (99 units) | 54 |

Community nurses

Parents will often long for the day they can take their baby home from hospital. However when this day comes around, moving away from all of the staff on the neonatal unit, and the support they provide, to look after their baby on their own can be a very worrying time for families.

The *Toolkit* states that all units should have access to staff skilled in caring for babies following neonatal care, and that these staff are available to provide support in the community to babies once they have left hospital. This support in the community means that some babies will be able to leave hospital earlier and prepares families for looking after their babies at home.

Just over half of units (53 per cent) said that they had nurses working in community outreach services: averaging just one nurse per unit. Four of these units said that these outreach services were provided by the paediatric outreach team.

These findings confirm what parents told us about the support they received when their babies left hospital. Only half (53 per cent) of parents had an agreed plan at discharge between themselves and community health professionals. More support for families is clearly needed.

Medical staffing

The *Toolkit* outlines the number of doctors of each grade needed for each of the three levels of neonatal unit. 14 units (15 per cent of those that responded to this question) reported current vacancies in their consultant grade rotas, totalling 16 whole time equivalent consultant posts.

Five units reported they had at least one consultant vacancy for over three months which they had not yet been able to fill, totalling 7.5 whole time equivalent consultant posts.

One unit reported that they had a vacancy which they had been unable to fill for over six months, for one whole time equivalent consultant.

“We have a plan to appoint eight new consultants... There are too few good candidates at any one time so it has been accepted that we will appoint these staff over one to two years.” (Consultant)



In addition seven units reported, without prompting, particular problems relating to a shortage of junior or middle grade doctors. Three of these units specifically mentioned that they had difficulty in attracting locum doctors at this level.

“Middle grade medical rota has been difficult to fill as there have been insufficient Deanery trainees and no appropriate locums in response to advert.” (Head of neonatal nursing)

A number of units attributed the problem to an inability to attract enough candidates to take forward neonatal medicine as a speciality. One attributed the problem to changes in regulations relating to recruitment of doctors from overseas.

“Recruitment of junior and middle grade doctors (is a) very high cause for concern exacerbated by the restrictions on overseas recruitment.” (Neonatal service lead nurse)

Three units reported that they had had to close to new admissions at least once in the month of June 2010 alone due to a shortage of middle grade doctors.

Access to other healthcare professionals

The *Toolkit* and most recent BAPM standards both set out that babies in neonatal care should have access to a wide range of other healthcare professionals in addition to nurses and doctors, known as allied health professionals, with specialist knowledge and training in neonatal care. We asked units if they had provided any access to a range of allied health professionals in the month of June 2010, to establish a snap shot of babies' access to these services at a recent point in time.

Two-thirds of units (66 per cent) told us that they had provided some access to physiotherapy and a further two-thirds (65 per cent) said babies had access to dietetic support in June 2010.

Less than half (45 per cent) provided speech and language therapy to babies in the month of June and just over one in four units (28 per cent) provided some level of access to occupational therapy to babies.

Less than half (49 per cent) of units said parents had access to counselling services in June 2010.

Closures and occupancy levels

Three out of four units (76 per cent) said that they had to close to new admissions at some point in 2009. 58 units provided information about the number of cots closed, and for how long, amounting to almost 10,700 cot days* in 2009.

Special care cots accounted for the highest number of closures, contributing to 6600 cot days. High dependency cot closures came to 980 and there were 2830 intensive care cot closures.

Local neonatal units were affected by more closures than the other unit levels, 5610 in total. There were 4410 closures in neonatal intensive care units and 670 in special care baby units.

To gain an understanding of the reasons for cot closures at a point in time, we asked units for information about of any closures in June 2010. 28 units reported cot closures amounting to 1040 cot days in this time period.

The key factors leading to cot closures in the majority of these units were staffing and capacity issues.

Cot closures due to staffing problems in one month

- 14 units reported cot closures due to nurse shortages, amounting to a total 305 days in the month of June.
- Three units reported four cot closures due to middle grade doctor shortages.
- One unit reported two cot closures in this period due to a shortage of consultants.
- 18 units reported 156 cot closures due to other capacity issues.

Occupancy

The *Toolkit* advises neonatal units to operate at no more than 80 per cent occupancy levels. This means 80 per cent of the cots that unit is officially funded and staffed to run are in use at any one time. The *Toolkit* highlights risks associated with running services over 80 per cent occupancy levels in terms of higher mortality levels.

*Cot days are a way of measuring the care provided in neonatal units. A cot day is calculated as number of cots x number of days.

Our 2008 report highlighted the pressures faced by intensive care units, in particular, running at 100 per cent occupancy or above. However this survey has identified that neonatal units across all levels are working well over capacity, with 80 per cent of units telling us they were running at an average occupancy of 100 per cent or over at some point in 2009.

12 special care baby units told us that their monthly occupancy levels for special care cots reached 100 per cent or above in 2009. Two of these units were each running at 100 per cent occupancy for a total of 11 months in 2009, and a further unit was operating at this level for six months of the year. Three special care baby units also reached 100 per cent occupancy within their high dependency cots. Many local neonatal units also reached 100 per cent occupancy levels in 2009 with 26 reaching full capacity in their special care cots, 22 in high dependency cots, and 14 in their intensive care cots.

However the problem is greatest in neonatal intensive care units. On average, neonatal intensive care units are running at 94 per cent occupancy and in some units reached over 200 per cent for extended periods.

More neonatal intensive care units were running at 100 per cent capacity or above than units of any other level. 28 out of 39 units reported running at occupancy levels of 100 per cent or over for at least one month in their special care cots, 22 out of 32 in high dependency, and 18 out of 39 in their intensive care cots.

Transfers

Transport services are an important aspect of neonatal care to ensure that babies and their mothers receive the care they need, where they need it. There have been some positive developments in recent years with the establishment of dedicated neonatal transport services across most of the country.

One of the main functions of neonatal networks is to coordinate the care of babies between a regional group of units of differing levels, to help ensure that mothers and babies are not transferred long distances across country to find a unit of the right levels with capacity to care for them. However sometimes it is necessary to transfer a mother or baby to a hospital outside of their network. Often this is because the care they need is highly specialised and therefore only available in certain parts of the country. However sometimes long distance transfers occur because units closer to home are too full to accept new admissions.

The transport services that responded to our survey reported that they conducted 640 transfers to units outside of their networks in 2009. 40 per cent of these transfers were due to clinical reasons, as set out above, and a further 40 per cent were for returning babies to their local unit or another appropriate unit in their home network. However six per cent of transfers to hospitals out of the network were due to capacity issues at the transferring neonatal unit.

The transport services also told us about the reasons for transfers of mothers and babies into their network areas. They reported that 90 per cent of transfers into hospitals in their networks from outside hospitals, were due to capacity issues in outside networks.

From a parent's perspective, almost half (43 per cent) of mothers who were transferred to another hospital before giving birth to their baby reported that this was due to lack of capacity. Parents also told us that one in five transfers of their babies was due to a lack of capacity.



Families' experiences of neonatal care

Having a baby admitted to neonatal care is an extremely stressful time for families. The *Parents of Premature babies Project (POPPY)*^{viii}, and the *Toolkit* set out the support and facilities that should be available to families. This section looks at to what extent these support services are available to parents.

Parent accommodation

In March 2010, a Government report set out the commitment that by 2015 parents with babies in neonatal care can be confident that overnight accommodation will be available to all who require it, so that both mothers and fathers can stay close to their baby^{ix}.

Almost all hospitals (96 per cent) have some overnight accommodation available to parents on or adjacent to the neonatal unit to enable parents to be close to their baby in the case of emergency. The average number of rooms available per hospital is 2.6.

In addition, a quarter of all units (24 per cent) have accommodation available within the ground of the hospital, averaging four rooms per hospital. A further six units provide hotel or hostel accommodation for parents.

While we welcome the fact that almost every unit is able to offer overnight accommodation of some kind, our findings from the survey of parents show that it is still not available to all who require it. 60 per cent of parents told us that accommodation was not available for the mother to use in or next to the unit. 53 per cent told us that accommodation for both parents in or next to the unit was not available.

The number of rooms per unit also falls short of the standard set out in the *Toolkit*. This states that, as a minimum, one room should be available for every intensive care cot 10 - 15 minutes from the unit. In addition two rooms should be available within or adjacent to the unit for 'rooming in', where the mother and father can stay in the same room as their baby, to build up their confidence as parents before taking their baby home.

We estimate at least a further 250 parent rooms are needed across England, for all units to meet the *Toolkit* standard.

Financial difficulties for families

Having a baby brings with it many additional costs for any family. However, parents whose babies are admitted to neonatal care face many further costs related to visiting their baby or babies in hospital and taking extra unpaid time off from work to do so.

Parents who responded to our survey told us that having a baby in neonatal care cost them, on average, an extra £2,800. This works out as an additional £310 per week, as our respondents' babies were on a neonatal unit for an average of nine weeks. This is on top of all the usual expenses related to a new baby. The average cost for the most frequently mentioned items are listed below.

Average costs for parents of babies in neonatal care

- **Travel:** £400
- **Food:** £240
- **Accommodation:** £110
- **Childcare:** £100 (this is important if the parents already have other children at home)
- **Car park:** £125
- **Loss of earnings:** £1,260
- **Other:** £565 (including phone calls, premature baby nappies, breast pumps etc)

The single most significant cost faced by families was loss of earnings. A number of parents reported that they or their partner could not work while their baby was in neonatal care. Needless to say, this had a major impact on their financial situation and many aspects of their lives.

Eight respondents told us that they had unsympathetic employers, leading to at least one father having to give up work to continue visiting his baby in hospital.

"More support is needed from the Government for families with premature babies - extended maternity/paternity leave and more support to get back into work so we are not forced to give up jobs and live off the benefit system." (Parent)

Travelling to hospital to see their baby was another major cost faced by families. More than a quarter of parents (26 per cent) had to travel between 11 and 30 miles to see their baby. 14 per cent of parents had to travel more than 50 miles to see their baby.

The *Toolkit* outlines that NHS Trusts have policies in place to provide financial support to families if their baby is in neonatal care for a long period or if their baby is transferred a long distance away from their local unit. Information about this financial support should be made available to families.

40 per cent of parents did not receive any form of financial help for these additional costs from their hospital. The most financial assistance given was in relation to car parking costs: 35 per cent reported that part of their car parking fees had been covered and 22 per cent had all of their car parking fees paid.

Awareness of these sources of support, where they do exist, is also lacking in some areas, as one parent illustrated:

“Parking cost £6 a day. No-one had told us that we could obtain a special £6 a week pass because our son was going to be a long stay patient. We were only told about this two weeks prior to our son being discharged when we had already spent in the region of £170.”(Parent)

Communication and information

The majority of parents reported that their baby’s medical condition and care were discussed with them. Three-quarters (75 per cent) reported that their baby’s medical condition was always discussed with them and just under a quarter (22 per cent) said this was discussed with them sometimes.

More than half of parents said that the equipment (52 per cent) and procedures (59 per cent) involved in their baby’s care was always discussed with them. However around a third of parents said these aspects of their baby’s care were only discussed with them sometimes (35 per cent and 33 per cent respectively).

More than one in ten parents (11 per cent) reported that they were not given any written information or booklets to help them understand the care their baby was receiving.

Skin to skin contact

The *Toolkit* states that parents must be supported to participate in their baby’s care, including providing skin to skin care for their baby. 45 per cent of parents had skin to skin contact with their baby daily, and 27 per cent had skin to skin contact every two to four days. However one in ten parents had no skin to skin contact at all with their baby.

Of those that had skin to skin contact, 21 per cent said that it always lasted as long as they wanted it to last and 44 per cent said it usually lasted as long as they wanted.

Breastfeeding

The health benefits of breastfeeding are well-known, and breast milk is even more beneficial for babies in neonatal care. Almost all parents (96 per cent) reported that there was sufficient space provided in the unit for breastfeeding, however only one in four (25 per cent) stated this was private and around one in three (31 per cent) said these facilities were comfortable.

Going home

Parents often tell Bliss that going home from hospital with their baby can be a very daunting experience as they leave the hospital environment with all of its equipment and the day to day support from a team of health professionals. Only two-fifths of parents (41 per cent) had any contact with their health visitor before discharge. And only half (53 per cent) had an agreed plan at discharge between themselves and a community health professional.



Conclusions

2010 is potentially a year of great opportunity for neonatal services in England. The Department of Health/NHS *Toolkit for High Quality Neonatal Services* has already established a comprehensive framework to provide the best possible care to babies and their families. The new NICE *Quality Standards* on specialised neonatal care build on the *Toolkit* and provides a set of indicators by which high quality care can be evaluated. Finally, the move towards maternity networks, hopefully stimulating better coordination between maternity and neonatal services, offers the potential of a brighter future for our most vulnerable babies.

However as this report identifies yet again, although the direction of travel is positive, the speed of delivery must be accelerated. There remain untenable shortages of neonatal nurses and doctors in England, meaning that units have to regularly work over agreed safe capacity levels or shut their doors to new admissions. This can no longer be acceptable. It puts frontline staff under unbearable pressure, impacts on the vital treatment of tiny babies, and increases the likelihood of families being moved long distances to find the care that they desperately need.

In the foreword to the *Toolkit*, Professor Sir Bruce Keogh, the NHS' Medical Director, states: "One of the measures of a civilised society is how well it cares for its most sick and vulnerable members; nowhere is this tested more than in neonatal services".

Commissioners must recognise the importance of high quality neonatal care to meet the challenge of delivering the best start in life to our children. Investment in reaching the *Toolkit's* standards is urgently required. Though as the Department of Health itself recognises,^x this investment will generate significant economic savings over the medium term.

The vital role of families within neonatal care must also be more clearly recognised. Long term plans must be put in place to deliver the practical, emotional and financial support and facilities to help families cope with this most challenging time of their lives.

Recommendations

- NHS commissioners set out comprehensive plans without delay, outlining how they will deliver the full recommendations of the Department of Health/NHS *Toolkit for High Quality Neonatal Services* by 2020, with clear timescales to support doctors and nurses with local implementation – this includes increasing nursing and medical staffing, provision of 24/7 transport services and support and facilities for families.
- The Coalition Government provides suitable oversight of the *Toolkit's* implementation to ensure that the standards are developed equitably across the country.
- Neonatal care is recognised as an integral part of new maternity networks, with all areas of care commissioned through the NHS Commissioning Board, in a coordinated fashion alongside maternity services.
- The Coalition Government recognises the commitment made by the last Government that "within the next five years parents with babies in neonatal care can be confident a bed will be provided for them, so that both mothers and fathers can stay close to their baby"^{xi}
- The vision for neonatal care set out in the *Toolkit* is made a top priority in the 2011/12 NHS Operating Framework.
- The Secretary of State for Health sets out in the 2011/12 NHS Outcomes Framework that all neonatal units make measuring outcomes of babies admitted to neonatal care at two years old and the experience of their parents of a priority.
- Regional and local NHS structures dedicate sufficient resources to ensure that shortages of both nursing and medical staffing are resolved through long term recruitment and training strategies.



Methodology

In July 2010, Bliss sent a survey to all 177 hospitals with a neonatal unit in England. We received a response from 116 units. This is a response rate of 66 per cent.

We asked 21 questions about the units' facilities, designation, staffing and occupancy, with a further two sections where respondents could add comments. Some questions related to the current staffing of the unit at the time of completing the survey, others referred to data for 2009. Further questions were focused on a particular month/week to get a snap shot of how services across the country are working at one time.

To calculate the number of nurses needed to care for the babies admitted in 2009, we used the average monthly occupancy rate for each level of care the hospitals provides, taken from their response to our survey. We divided this figure by 30.42 to work out the average number of occupied cots per day. We then applied the following formula to calculate the number of nurses needed according to the BAPM 2001 standard:

$$((\text{number of intensive care cots}) + (\text{number of high dependency cots}/2) + (\text{number of special care cots}/4) + 1) \times 5.75$$

All posts in this report refer to whole time equivalent positions.

A survey was also sent to all neonatal transport services to find out about services' operating hours, and number of transfers undertaken. Responses were received from ten transport services.

Also in July, Bliss posted a survey on our website asking parents to tell us about their experiences of having a baby in neonatal care. Over 600 parents responded to this request for information. Of these, 301 were from parents who have had a baby or babies in neonatal care between January 2008 and July 2010. It is from these 301 parents with more recent experience of services, that the findings in this report related to families' experiences of neonatal care are based.

Percentages given are calculated using the total number of responses received to each specific question, and are rounded up or down to the closest whole number.

Cot day closures are rounded to the nearest ten and costs to parents are rounded to the nearest £5.

References

ⁱ *Toolkit for High Quality Neonatal Services*, NHS and Department of Health (November 2009)

ⁱⁱ There were 671,058 lives births in England in 2009 according to the *Birth summary tables for England and Wales*, Office for National Statistics (July 2010)

ⁱⁱⁱ *Baby Steps to Better Care: England briefing*, Bliss (October 2008)

^{iv} *Standards for Hospitals Providing Neonatal Care*, British Association of Perinatal Medicine (1996), *Standards for Hospitals Providing Neonatal Care* (Second Edition), British Association of Perinatal Medicine (December 2001), *Standards for Hospitals Providing Neonatal Care* (Third Edition), British Association of Perinatal Medicine (August 2010)

^v Bliss Baby Reports: *Three Decades and Counting* (November 2009), *Baby Steps to Better Care* (October 2008), *Too little, too late?* (2007), *Weigh less, worth less?* (2006), *Special care for sick babies... choice or chance?* (2005)

^{vi} *Standards for Hospitals Providing Neonatal Care* (Second Edition), British Association of Perinatal Medicine (December 2001)

^{vii} *Baby steps to better care: England briefing*, Bliss (2008)

^{viii} *Family centred care in neonatal units: a summary of research results and recommendations from the POPPY project*, Bliss, NCT, NPEU, RCN and the University of Warwick (2009)

^{ix} *Maternity and Early Years: Making a good start to family life*, HM Government (March 2010)

^x *Impact Assessment of Principles for Quality Neonatal Services*, Department of Health (November 2009)

^{xi} *Maternity and Early Years: Making a good start to family life*, HM Government (March 2010).





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