# Networks, admissions and transfers: the perspectives of networks, neonatal units and parents

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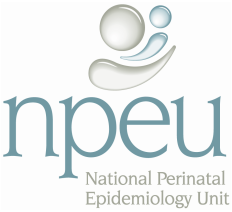


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# Executive Summary

A national survey of neonatal units commissioned by BLISS was designed and developed at the National Perinatal Epidemiology Unit. The 2006 survey focused on fundamental issues associated with the organisation of neonatal care, transfers and the role of neonatal networks. It followed on from a survey completed in 2005, also by NPEU, looking at policy and organisation. Questionnaires were also sent to network managers and interviews held with a number of lead clinicians and nurses in a subset of neonatal units and networks. The response rate for the UK units was 78% and managers for all the functioning neonatal networks returned questionnaires. Data from 350 parents came from a web-based survey.

## Key findings

### Neonatal managed clinical networks

- Reconfiguration of neonatal services is ongoing
- There is evidence of some streamlining of care and remodelling of unit capacity
- The extent to which functioning managed clinical networks have become established in neonatal care is variable
- The financial basis of network functioning is of concern to units, clinicians, network managers and leads, especially in the context of payment by results
- Shared meetings, staff training and the development of shared protocols are the most commonly reported aspects of successful of network functioning
- Transport services have been recognised as a key aspect in network and supra-network functioning

### Neonatal unit capacity

- UK neonatal admission rates continue to rise
- Some small units have closed and further closures are planned
- Almost all study units commonly exceed their capacity
- Level 1 (Type 1) units are admitting babies requiring intensive care
- 7% of all extremely low birth weight (ELBW) were admitted to Level 1 (Type 1) units
- Three-quarters of units had been closed to admissions at some time in the six months prior to the survey

### Neonatal Unit staffing

- The most frequently reported capacity problem is inadequate nurse staffing
- Although nurse staffing figures have increased since 2005, the nurse workforce in whole time equivalents (WTEs) is understaffed by a third
- Only 4% of neonatal units meet the British Association for Perinatal Medicine (BAPM) standards put forward for nurse staffing

## Neonatal transport and transfers

- The need for specialist services and capacity in the hospital in which a baby was born are the main reasons for transfer (excluding back transfers)
- Dedicated transport services are not universally available and services shared across networks are operating or being planned in some areas
- The need for accurate data collection on transfers, including ‘in utero’ transfers is critical for planning and auditing the service

## Parents’ needs

- Parents need to be considered and to be fully informed about the transport process
- Relatively few parents are aware of neonatal networks and of possible impact of network organisation on the transfer of their baby
- Parents value enormously the care that is provided for their babies, however the specific support, information and practical needs of parents whose babies are moved between units should be addressed

The findings of the study, while reflecting changes in neonatal services, also call attention to the continuing need for more neonatal cots and specialist staff. At the same time they point towards a need for a more co-ordinated approach to network management and operation, as well as a drive to address the nurse staffing issues in neonatal care. The main benefit of networks so far seems to have been the open dialogue and communication between neonatal units involving shared learning and evidence-based protocols for clinical care. Changes to care and outcomes for babies may have occurred as a consequence, but the evidence is not yet available about any benefits arising from network introduction and development.

# Section 1: Introduction

In April 2003 the Department of Health published a review of neonatal intensive care[1]. This report described the challenges facing neonatal services and concluded that the current organization and delivery of care was unsustainable. It described the organisational changes and defined levels of care, staffing, resources and parental support and information required to deliver a more continuous, equitable service. In particular, it recommended the following as key elements in developing a high quality, neonatal service:

- Establishing clinical networks that would provide access to appropriate and high quality care for all families
- Defining clearly the type of care that babies might require: special care, high dependency and intensive care
- Designation of units to provide levels of care e.g. some units would only provide special care, most would provide high dependency and limited intensive care and some, the full range of intensive care.
- Stopping inappropriate transfers of babies out for intensive care; ensuring that babies with complex care needs or requiring long periods of respiratory support are cared for initially in a level 3 unit (especially for babies born at 27 weeks gestation or less)
- Establishing staffing levels with new ways of working and working towards a greater consultant presence in level 3 units
- Recommending an increase in cot capacity in the units providing intensive care and strengthening the role of SCBU to provide high quality special care for babies.

In July 2005 a survey of policy and organisation in neonatal care in the United Kingdom was completed which indicated a variable and, in many areas, disjointed approach to neonatal care. [2] Neonatal networks have been introduced in England, however, they appear to vary in funding arrangements and set-up, as well as in function and operation.

Advocates of clinical networks suggest that they can make more efficient use of staff; reduce rigid professional boundaries; allow good practice to be shared; put patients at the centre of care; and improve access to care.[3] However, there is as yet, limited understanding of the impact of networks on patient care or much evidence on the most appropriate ways to organise and manage networks in health care.[4] The aim of this study was to carry out an assessment of unit activity, network management and operation in neonatal care as currently operated from a number of perspectives.

[1] Department of Health. *Neonatal Intensive Care Review: Strategies for Improvement.* Available at: http://www.neonatal.org.uk/NR/rdonlyres/0AB42821-0B13-4E19-B7A4-612C953154D4/33760/neonatalapr03.pdf
[2] Redshaw, M & Hamilton, K. A survey of current neonatal unit organisation and policy (2005) NPEU. Available at: www.npeu.ox.ac.uk
[3] NHS Confederation. *Clinical Networks*. NHS Confederation. 2002; 8.
[4] Goodwin N, Perri 6, Peck E, Freeman T, Posaner R. *Managing across diverse networks: lessons from other sectors. Research and Policy Report*. Birmingham: University of Birmingham, Health Services Management Centre; 2004.

# Section 2: Methods

## 2.1. Participants

### 2.1.1 Neonatal Units

A survey of neonatal units was designed and developed, based on previous research, which focused on network participation and functioning, capacity, admissions and transfers. Early in 2006 questionnaires were sent to senior nurses in all 218 neonatal units in the United Kingdom, previously identified in the 2005 NPEU neonatal survey.[1] Exclusions included midwifery-led units without neonatal care, units that had amalgamated, units that had closed and a large specialist unit located in a children's hospital. Four further units had closed or merged. Follow-up was by email or telephone and a repeat mail out to named personnel.

A 78% response rate was achieved in the unit survey. The questionnaires were completed by unit managers, senior nurses, neonatal nurse practitioners and clinicians, often jointly. Responses by country are shown in Table 2.1. Comparable data are also shown for the 2005 survey.

| COUNTRY | **2006 Data n (%)** | **2005 Data n (%)** |
|---|---|---|
| England | 139/179 (78) | 128 (70) |
| Scotland | 12/15 (80) | 12 (80) |
| Wales | 9/13 (69) | 8 (57) |
| Northern Ireland | 6/7 (86) | 5 (71) |
| TOTAL | 166/214 (78) | 153/218 (70) |

**Table 2.1 Response rate by country and overall**

### 2.1.2 Neonatal Networks

A questionnaire was developed for network managers, covering similar content areas. Thus at the same time that neonatal units were sent questionnaires, managers in the 23 English neonatal networks were also sent questionnaires about the networks for which they were responsible. Of the 23 neonatal networks, one was unable to participate, due to the recent dissolution of the network management structure. The nature and stage of development of networks in Scotland, Wales and Northern Ireland, meant that the questionnaire designed for network managers was not appropriate at this time.

[1] Redshaw, M & Hamilton, K. A survey of current neonatal unit organisation and policy (2005) NPEU (www.npeu.ox.ac.uk)

An interview schedule was also developed and used with lead clinicians and nurses in a small subset of neonatal units and networks.

#### 2.1.3 Parents

Data on parents' experience of neonatal care, admission and transfers were collected from more than 350 families whose infants had been admitted to a neonatal unit in the last two years. A web-based survey on the BLISS website was used. Basic demographic data were collected and details about admission, care and length of stay, information and knowledge about neonatal care, transfers, transport and networks, use of facilities, travel and concerns arising from these aspects of neonatal care. Where infant data were requested parents of multiples were asked to provide information about the first infant.

### 2.2. Data analysis

The analyses contained in this report are based on the responses to the surveys, with additional information about cots and admissions for non-respondents utilising the Directory of Critical Care. Largely descriptive data are presented.

As part of the move to networks most neonatal units have been designated as Level 1, 2 or 3, with the last of these routinely providing intensive care for large numbers of babies. Not all designation had been agreed at the time of the survey and some planned changes in status had not taken place. Thus, as with the 2005 survey, the units were categorised as Type 1, 2 and 3 in a parallel way, based on the numbers of cots and type of care provided and the criteria put forward in the 2003 Department of Health review[1]. This enabled comparisons to be made between types of unit. (Throughout the report IC indicates intensive care, HD high dependency and SC special care.)

Statistical analysis was carried out using SPSS version 12 software. Similarities and differences between the different types of unit were explored by using appropriate univariate analyses. Statistical significance was set at p=<0.05.

[1] Department of Health. *Neonatal Intensive Care Review: Strategies for Improvement.* Available at: http://www.neonatal.org.uk/NR/rdonlyres/0AB42821-0B13-4E19-B7A4-612C953154D4/33760/neonatalapr03.pdf

# Section 3: Neonatal Managed Clinical Networks

## 3.1. Introduction

Managed Clinical Networks were introduced in the National Health Service following the Calman Hine report on cancer services in England, and the Acute Services Review for Scotland as a means of encouraging more widespread integration of services and improvement in quality of care. [1,2] The concept of Managed Clinical Networks is now well established in other sectors, and they have been defined as:

> *"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".* [3]

The four components of networks are collaboration, co-ordination, equity and quality.

Following a review of neonatal services in England in 2003, which recommended that Managed Clinical Networks were the best way forward for neonatal care by promoting high quality care and integrated service delivery, national policy explicitly steered provision toward neonatal networks. [4]

## 3.2. Network Setup

The time taken to set up the neonatal networks in England has been variable. The majority of network lead and manager posts are funded through DH allocation and all 22 responding networks have functioning network boards with board chairs. Three of the networks are using the BLISS parent packs to facilitate parental involvement on the network board.

The way in which networks are organised is variable: in half of the networks the manager is employed full-time and in half part-time, with considerable variation in hours (some as low as .2 in the neonatal network manager post). All the networks have a lead clinician in post, although only half have a lead nurse. For many networks, the set-up process has been turbulent and a third had experienced personnel changes in initial appointments.

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[1] Calman K, Hine D. A Policy Framework for Commissioning Cancer. London: Department of Health; 1995.
[2] Goodwin N, Perri 6, Peck E, Freeman T & Posaner R. Managing across diverse networks: lessons from other sectors. Final Report. Birmingham: University of Birmingham, Health Services Management Centre; 2003.
[3] Scottish Executive Health Department. *Introduction of Managed Clinical Networks within the NHS in Scotland.* Available at: http://www.show.scot.nhs.uk/sehd/mels/1999_10.htm.
[4] Department of Health. *Neonatal Intensive Care Review: Strategies for Improvement.* Available at: http://www.neonatal.org.uk/NR/rdonlyres/0AB42821-0B13-4E19-B7A4-612C953154D4/33760/neonatalapr03.pdf

*'Having dedicated Network personnel has been essential in moving forward issues.'*

In many networks, the lead clinician had a significant role in co-ordinating the network development and its acceptance by the neonatal community.

*'We have a strong lead clinician with a track record of broad, non-partisan thinking. I think that has been a major strength for us.'*

For some clinical leads the continuous need for negotiations and managing interpersonal relationships has been demanding:

'*I feel I have spent a lot of time trying to settle differences between the lead centres who are overly competitive and the chances of them agreeing to any new thing is very small. I find that pretty frustrating.'*

All networks are operating through working groups with specific remits. As illustrated in Figure 3.1 The most common groups are those on commissioning, breastfeeding and guideline development.

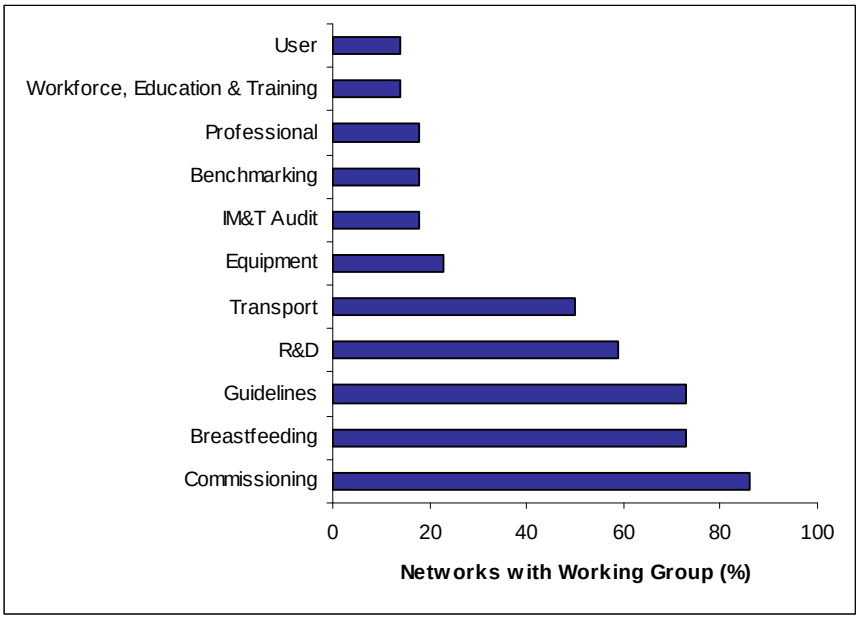


**Figure 3.1 Network Working Groups (n=22 neonatal networks)**

### 3.2.1 Key Concerns In Setting Up Networks

Following the publication of the Department of Health report, recurrent funds of approximately £20m per annum from 2006 have been provided to develop neonatal care, which included supporting neonatal networks, though this funding has not necessarily been clearly identified as going to neonatal care. For some of the staff involved, the way in which networks were advocated and funded has been problematic:

*'Another difficulty is that the network was imposed, and it was imposed with money.'*

*'The money allocated has not been used to develop neonatal care… it is lost for ever.'*

From the network perspective the four most frequently identified key concerns in setting up were: deskilling of staff in units providing only special care or limited intensive care (80% responses); downgrading of units (80%); changes in nurse staffing (70%) and in medical staffing (60%). Similar issues were identified by senior staff in neonatal units and the responses, grouped according to unit type, are shown Figure 3.2. A dominating concern related to the possible de-skilling of staff in units where the opportunity for caring for infants in intensive care was likely to be less. For Type 2 and Type 3 units a major concern was a change in unit status.

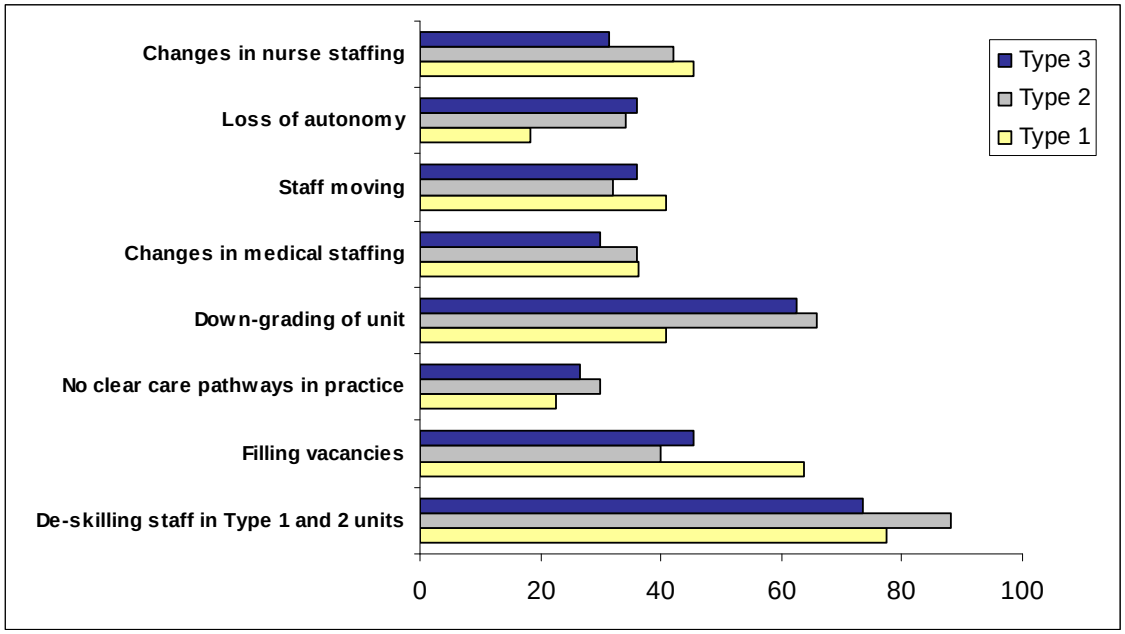


**Figure 3.2 Proportion (%) of units with specific concerns in relation to setting up managed clinical networks for neonatal care (n=136 units)**

### 3.3. Network Operation

A total of 22 neonatal networks were functioning in England at the time of the survey. The reported focus of network activity has largely been based on resource and capacity planning, closely followed by staff training and guideline development, outlined in Figure 3.3.

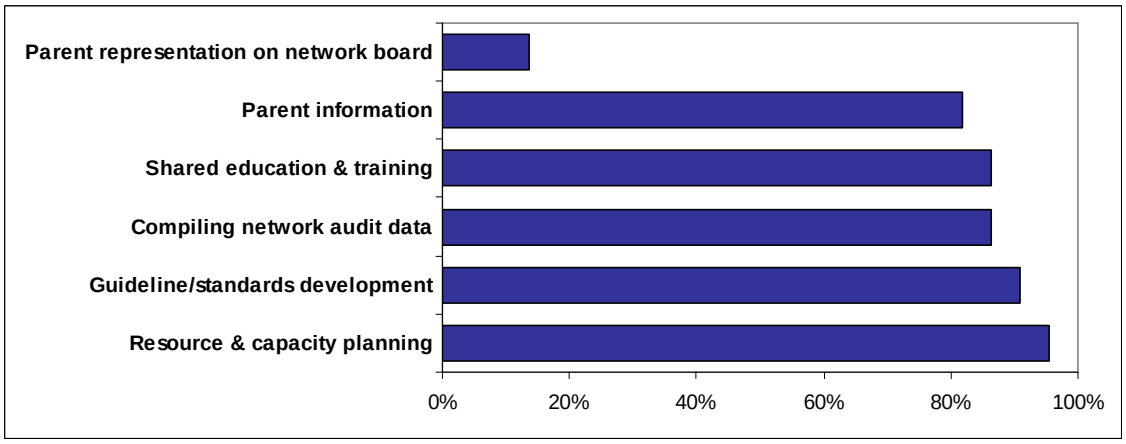


**Figure 3.3 Network features and activity (n=22 neonatal networks)**

### 3.3.1 Resource and Capacity Planning

An initial and necessary starting point for most networks was the review of existing services. The DH recommendations were that networks would ensure that groups of hospitals and neonatal units provide various levels of care whilst working together within a locality to improve the services provided to babies and their families. Following extensive and lengthy consultations, unit designation for the majority of networks has been approved, although for 3 networks designation of the Level 3 centres has not yet been agreed.

> *'We are at the analysis stage of the public consultation we have been very actively engaged in for the last 12 months. We have received over 53,000 formal written responses to our document, we have made over 18,000 face-to-face contacts through nearly 800 meetings and we have received petitions totalling over 130,000 signatures'*

Unit designation was defined according to the majority of care provided in the unit:

Level 1: Special care
Level 2: High Dependency and Short Term Intensive Care
Level 3: Neonatal Intensive Care

The average number of units per network is 7 (range: 5-12). There is evidence of some streamlining of care with many units reporting changes to capacity and cot designation. Four networks reported having no Level 1 units.

The majority of units in networks indicated that this process had been difficult and in some cases, demoralising for staff.

> *'We have had a huge battle to secure level 2 status for our unit.'*

> *'Staff morale is very low and people are uncertain of the future of maternity and neonatal services at this hospital.'*

### 3.4. Network Initiatives

As a consequence of the introduction of the networks, network managers identified several new initiatives (Figures 3.4 and 3.5). The development of a network wide or supra-network, dedicated transport systems was recognised as significant by many. Similarly agreement about evidence-based care was documented in the development and use of agreed and shared protocols across the network. Joint meetings were seen as a key benefit to their own local service and the network more generally, facilitating discussion, agreement and moves toward collaborative practice.

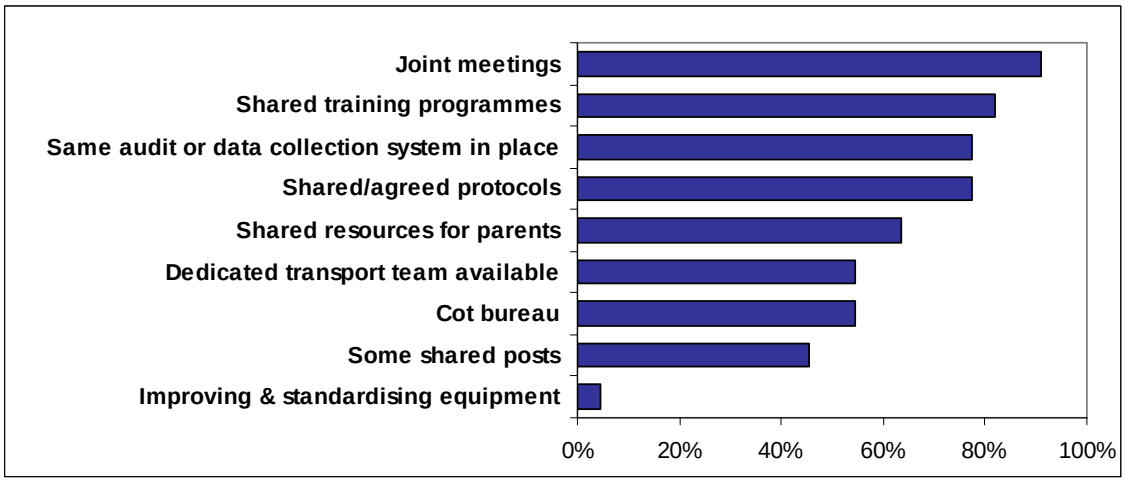


**Figure 3.4 Network New Initiatives (n=22 neonatal networks)**

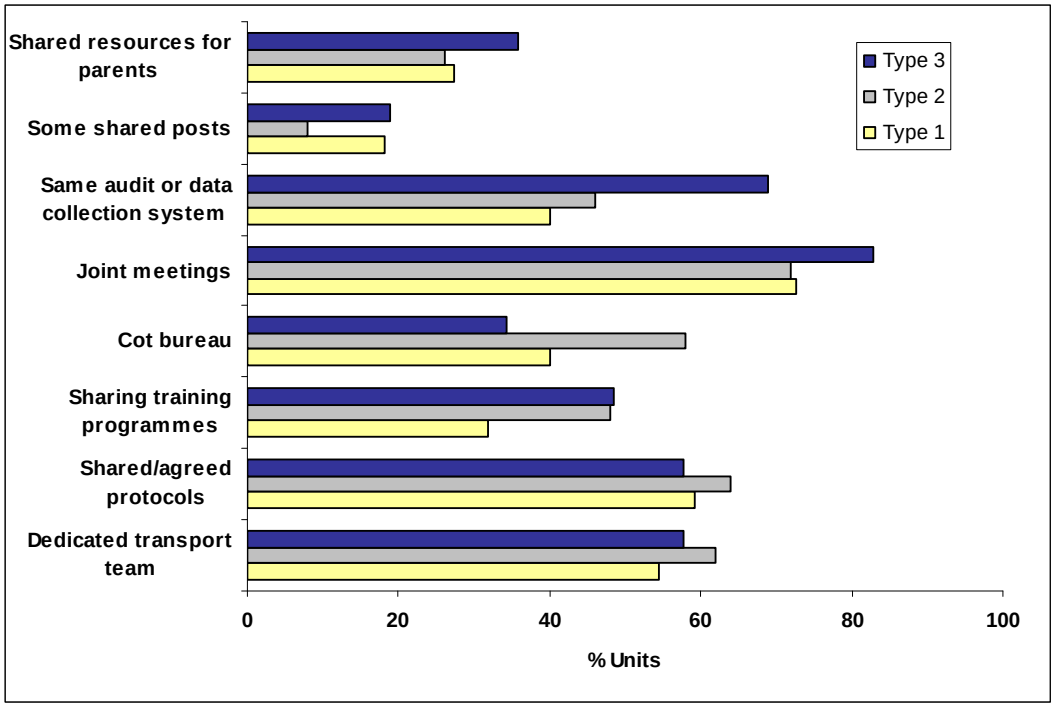


**Figure 3.5 The recognised benefits of neonatal networks to date (n=136 units in England)**

## 3.5. The Network Experience

> *'I see the network as an instrument of change to follow the Department of Health guidelines for the regionalisation of smaller babies. I also feel there will be benefits in terms of care from closer working together and to some extent I still hope that efficiency in terms of cost of the networks may be optimised by the managers working together'*

Respondents to both the network and unit questionnaires rated how effectively their network was functioning on a five point scale. Almost all the network managers felt that their network was functioning "quite well", with one indicating "sometimes well, sometimes not". Comparable data from the perspective of individual units, as represented by senior nurses or nurse managers, are shown in Figure 3.6. Most responses were in the middle range, with respondents in the Type 1 units having a more positive view. While relatively few were seen as working 'very well' (13%), nearly half (48%) of units described their network as working 'quite well', and at the other end of the scale a few units (9%) saw the network as performing 'not very well' or 'not at all well'. The unit perspective was thus a little less optimistic about the present level of working when compared with the network managers.

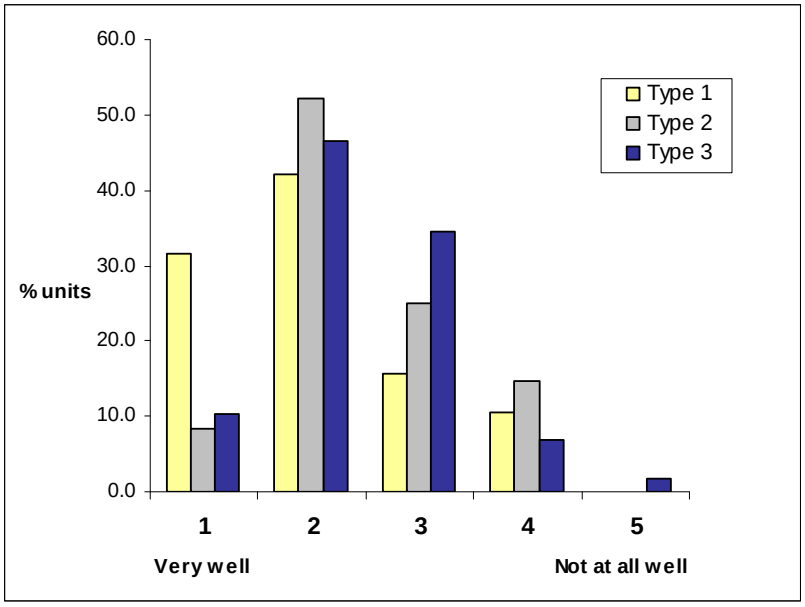


**Figure 3.6 Effectiveness of neonatal network functioning (n=125 units in England)**

Views about the experience of the networks are illustrated in Figures 3.7-3.10. Positive aspects of network experience are shown in Figure 3.7 from the network manager perspective and in Figure 3.8 from the unit perspective.

> *'Improved communication has lead to a much more interactive approach between units. There appears to be much more dialogue with the sharing of information and experiences and a more challenging approach to practices as everyone appears to be more open. We have a sense of strategic direction for all units in the network and greater support for those units who request it.'*

The emphasis in the responses was on communication and collaboration, with improved relationships between units within the network, and on the quality of care for babies that was now being provided. The network was seen as providing a mechanism for sick and vulnerable babies being cared for more effectively by staff with appropriate skills and experience, utilising standards that could be applied across the network.

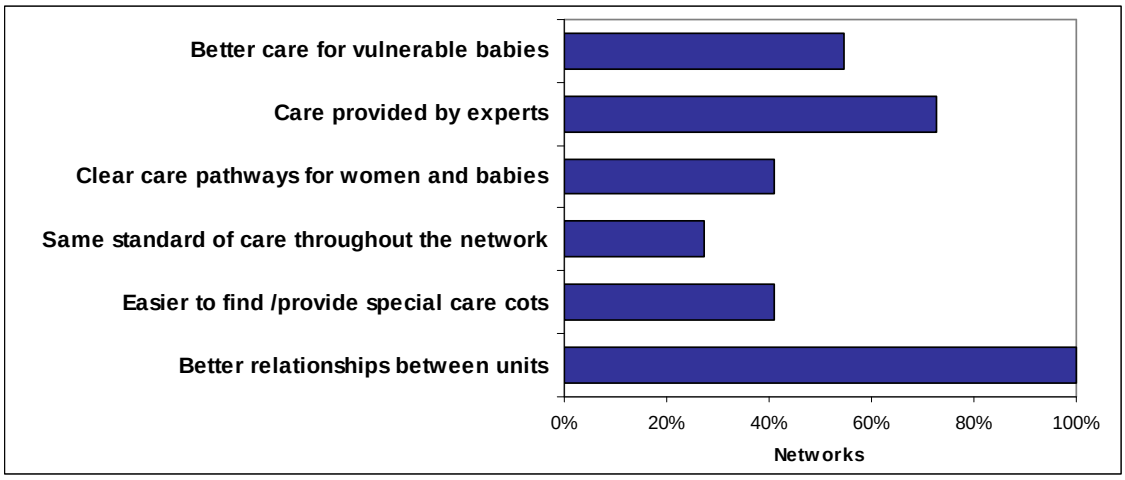


**Figure 3.7 Positive aspects of network experience from a network manager perspective (n=22)**

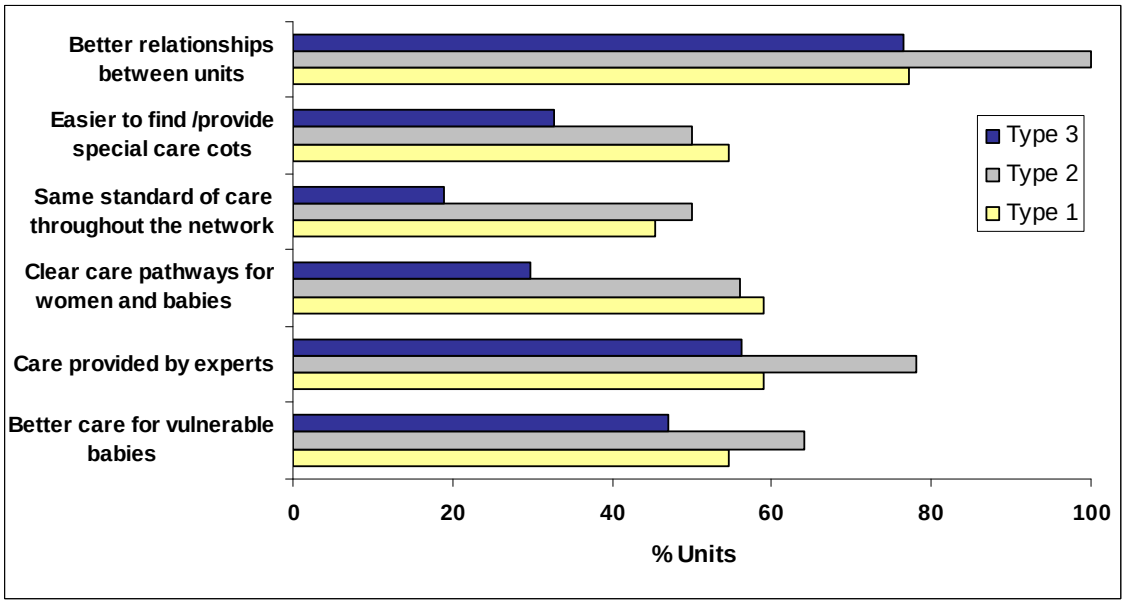


**Figure 3.8 Positive aspects of network experience from a unit perspective (n=136 units in England)**

Less positive aspects of network functioning are highlighted in Figures 3.9 and 3.10. The implications of network organisation that relate to the need for transfer are those which concerned many unit managers and senior staff, particularly those in Type 2 units.

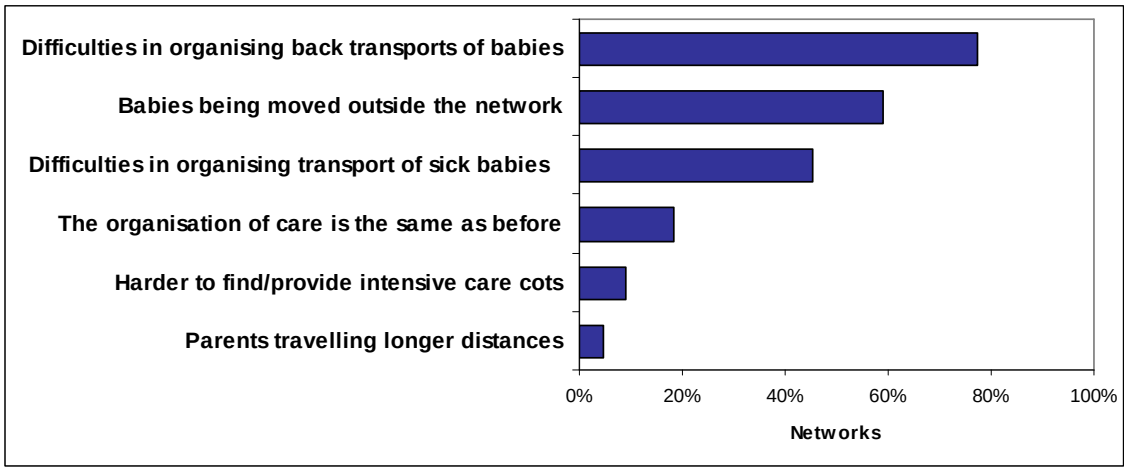


**Figure 3.9 Negative aspects of network experience from network manager perspective (n=22)**

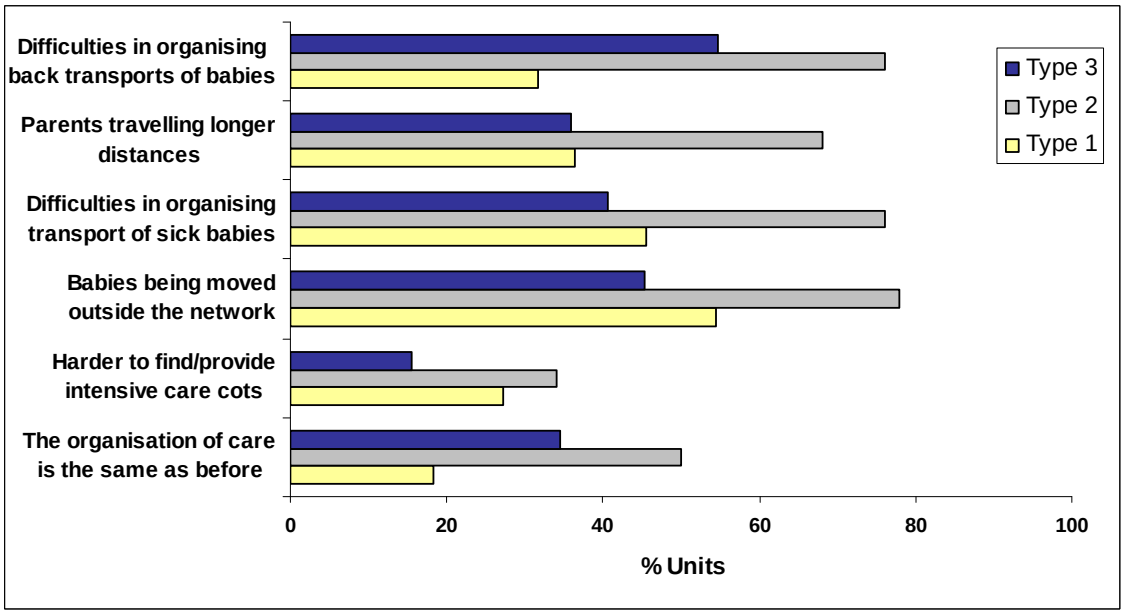


**Figure 3.10 Negative aspects of network experience from unit perspective (n=136 units in England)**

Some network leads, managers and unit respondents expressed uncertainty about the future:

> *'The Network has gone through an agreed designation process and agreed levels of care but is struggling to move forward on this due to uncertainty of funding and lack of support'*

> *'We are awaiting a decision on reconfiguration of neonatal and paediatric services in the region which will obviously have an impact on the service we provide. Decision due December 2006'*

*'The hospital has amalgamated with other hospitals to form one huge trust. The trust is also awaiting reconfiguration of services. Currently in the phase of a public consultation.'*

*'The process of designation of Level 3 units has been a lot slower than we would have liked. This has now slowed even further due to Payment by Results and yet another re-organisation of the NHS…'*

Some were concerned about the impact on staff and parents:

*'Given the resources, the unit is well able to cope with all babies born locally. There is no evidence to show that babies do better in larger units. It is heartbreaking to send a newborn 25 weeker on a pointless journey to adhere to current policy. I feel desperately sorry for parents who have a dreadful situation compounded by an 80 mile journey'.*

*'A great deal of time is spent on ensuring adequate staff cover and skill mix. Staff at Hospital X are sometimes expected to work at the Y Baby Unit when their staffing levels are inadequate. This does cause problems when staff have family commitments, with the travel to the other unit and different shifts.'*

However, some respondents felt supported or encouraged by the changes associated with the network developments

*'Network visit highlighted insufficiencies in nurse staffing and medical split site working, so extremely valuable in taking to board level'*

*'Clear pathways are starting to be developed - good practice. Due to being in a rural area we tend to keep some high dependency babies although not funded for them.'*

*'A retrieval service is being organised. A peer review of our neonatal service has taken place. Network option appraisal of neonatal services with unit redesignation and cot reconfiguration are ongoing.'*

*'Prior to network all hospitals worked in isolation. Now good support from nursing colleages in other units. Sharing information and equipment now takes place. Looking forward to when network has its own designated transport team.'*

*'Major review underway at present so final decisions re unit designation not yet taken. Network has made major investment in transport team with great success.'*

It seems that many staff at network and unit level have accepted the numerous changes that are taking place currently and appreciate the benefits they have seen so far.

# Section 4: Neonatal Unit Capacity

## 4.1. Unit Size

The data collected and presented on unit capacity come from units across the UK. A key indicator of the provision of neonatal care and its adequacy is the number of neonatal cots currently available in the neonatal service. The total number of cots in the UK is currently 3855, which equates to an average total number of cots per unit of 18 (sd. 8.0, range 2-48). Data from 2005 indicated that the total number of cots previously available in the UK was 3894. Thus with the closure of 4 units since 2005, the total number of neonatal cots has decreased by 39. Table 4.1 shows the distribution of cots in 2005 and 2006 by region for the 214 units currently open. On average, Scotland continues to have the largest number of cots per unit, while Wales continues to have the smallest (mean: 23 versus 14 cots respectively).

| Region | 2005 | | | 2006 | | |
|---|---|---|---|---|---|---|
| | Total Cots | Unit Mean (s.d.) | Range | Total Cots | Unit Mean (s.d.) | Range |
| **England** | 3215 | 17.9 (7.5) | 6-48 | 3230 | 18.0 (7.7) | 6-48 |
| **Scotland** | 340 | 22.7 (9.6) | 8-44 | 345 | 23.0 (9.7) | 8-44 |
| **Wales** | 184 | 14.1 (7.6) | 2-27 | 177 | 13.6 (6.9) | 2-27 |
| **N. Ireland** | 111 | 15.9 (11.2) | 6-39 | 103 | 14.7 (6.5) | 6-31 |
| **TOTAL** | 3850 | 18.0 (7.9) | 2-48 | 3855 | 18.0 (8.0) | 2-48 |

**Table 4.1 Cot distribution by country in 2005 and 2006 (n=214 neonatal units)**

## 4.2. Unit Capacity

A priority for effective delivery of neonatal care is access to appropriate care, thus with a concentration of skills and expertise where they are required. Unit capacity depends on the ability of a unit to treat and provide care for the range of illness and degree of prematurity required. This has been traditionally represented by the types of cot available in an individual neonatal unit: special care, high dependency care and intensive care.

For the 166 units in the 2006 survey, the distribution of cots designated for different types of care overall was: 21% of cots for intensive care, 15% for high dependency care and 64% for special care. There was no significant difference between the distribution of cots in respondent compared with non-respondent units (Table 4.2).

| Type of Cot | Respondent Units | | | Non-respondent Units | | | Difference *p** |
|---|---|---|---|---|---|---|---|
| | Total Cots | Mean (s.d.) | Range | Total Cots | Mean (s.d.) | Range | |
| **Intensive Care** | 629 | 3.8 (3.5) | 0-16 | 176 | 3.7 (3.4) | 0-15 | 0.83 |
| **High Dependency Care** | 455 | 2.8 (3.0) | 0-18 | 110 | 2.3 (2.6) | 0-10 | 0.35 |
| **Special Care** | 1895 | 11.4 (4.5) | 2-24 | 561 | 11.7 (4.4) | 3-25 | 0.71 |

**Table 4.2 Cot type in respondent and non-respondent neonatal units**

## 4.3. Unit Type

As with the previous NPEU report on neonatal care[1], the categorisation of units was derived using the BAPM Standards for Hospitals Providing Neonatal Intensive and High Dependency Care (2nd Edition), referred to in the Report of the Neonatal Intensive Care Services Review Group. [2,3,4] The designation in that review describes the different levels of care as follows:

> **Level 1 Units** provide Special Care but do not aim to provide any continuing High Dependency or Intensive Care.
>
> **Level 2 Units** provide High Dependency Care and some short-term Intensive Care as agreed within the network.
>
> **Level 3 Units** provide the whole range of medical neonatal care but not necessarily all specialist services such as neonatal surgery.

For the purpose of the analysis units were categorised according to unit "type" using the following criteria:

> **Type 1**: Special Care and $\leq$ 2 High Dependency Care Cots
>
> **Type 2:** Special Care, High Dependency & $\leq$3 Intensive Care Cots
>
> **Type 3:** Special Care, High Dependency & >3 Intensive Care Cots

Overall, 21% (n=44) of current UK units are Type 1, 34% (n=73) Type 2 and 45% (n=97) Type 3. The distribution of responding units by type did not differ: of the 166 responding, 20% (34) were Type l, 34% (57) Type 2 and 45% (75) Type 3 (Table 4.3).

[1] Redshaw M, Hamilton K. A survey of current neonatal organisation and policy July 2005. Available at: http://www.npeu.ox.ac.uk/neonatalunitsurvey/

[2] British Association of Perinatal Medicine. *Standards for Hospitals Providing Neonatal Intensive and High Dependency Care* (Second edition - December 2001). 2001. London, British Association of Perinatal Medicine.

[3] British Association of Perinatal Medicine. *Standards for hospitals providing neonatal intensive care.* 1996. London, British Association of Perinatal Medicine.

[4] Committee on Fetus and Newborn. Levels of Neonatal Care. *Pediatrics* 2004; 114(5):1341-1347.

| Unit Type | 2005 UK units | | | 2006 UK units | | |
|---|---|---|---|---|---|---|
| | % (n) units | Total No. Cots | | % (n) units | Total No. Cots | |
| | | Mean (s.d.) | Range | | Mean (s.d.) | Range |
| **Type 1** | 20.2 (44) | 10.7 (3.5) | 2-21 | 20.6 (44) | 10.3 (3.2) | 2-18 |
| **Type 2** | 34.9 (76) | 14.2 (4.3) | 6-28 | 34.1 (73) | 14.5 (4.1) | 6-28 |
| **Type 3** | 45.0 (98) | 24.0 (6.9) | 14-48 | 45.3 (97) | 24.1 (7.1) | 12-48 |
| **TOTAL** | 218 | 17.9 (7.9) | 2-48 | 214 | 18.0 (8.0) | 2-48 |

**Table 4.3 Cot distribution by unit type in 2005 and 2006**

The distribution of cots for each type of unit in 2006 compared with 2005 data are shown in Table 4.3. In general there appears to be little difference in the overall average size of units (as denoted by the number of cots per unit) between 2005 and 2006. Data from the matched units (Table 4.4), responding to the 2005 and 2006 surveys present the same picture.

| Unit Type | Matched Respondent Units 2005 | | | Matched Respondent Units 2006 | | |
|---|---|---|---|---|---|---|
| | % (n) units | Total No. Cots | | % (n) units | Total No. Cots | |
| | | Mean (s.d.) | Range | | Mean (s.d.) | Range |
| **Type 1** | 19.3 (24) | 10.0 (3.0) | 2-16 | 20.1 (25) | 10.3 (3.7) | 2-18 |
| **Type 2** | 37.9 (47) | 14.5 (4.4) | 6-28 | 37.1 (46) | 14.5 (4.3) | 6-28 |
| **Type 3** | 42.8 (53) | 24.9 (7.4) | 15-48 | 42.8 (53) | 25.0 (7.4) | 14-48 |

**Table 4.4. Overall cot distribution by unit type in matched units (n=124 neonatal units)**

The current distribution of special, high dependency and intensive care cots in the UK is shown in Table 4.5

| Unit Type | No. Special Care Cots | | No. High Dependency Care Cots | | No. Intensive Care Cots | |
|---|---|---|---|---|---|---|
| | Mean (s.d.) | Range | Mean (s.d.) | Range | Mean (s.d.) | Range |
| **Type 1** | 9.7 (3.3) | 2-18 | 0.6 (9.2) | 0-2 | 0 (0) | 0 |
| **Type 2** | 10.3 (3.7) | 2-20 | 2.0 (1.8) | 0-8 | 2.1 (0.8) | 0-3 |
| **Type 3** | 13.1 (4.8) | 4-25 | 4.1 (3.4) | 0-18 | 6.8 (3.0) | 2-16 |
| **TOTAL** | 11.5 (4.5) | 2-25 | 2.6 (2.9) | 0-18 | 3.8 (3.5) | 0-16 |

**Table 4.5 Cot types for all UK neonatal units (n=214)**

| Unit Type | 2005: total (mean) | | | | 2006: total (mean) | | | |
|---|---|---|---|---|---|---|---|---|
| | Total Cots | SC Cots | HDC Cots | IC Cots | Total Cots | SC Cots | HDC Cots | IC Cots |
| **Type 1** | 239 | 219 (9.1) | 19 (0.8) | 1 (0.1) | 258 | 238 (9.5) | 20 (0.8) | 0 (0) |
| **Type 2** | 682 | 483 (10.3) | 104 (2.2) | 95 (2.0) | 669 | 484 (10.5) | 89 (1.9) | 96 (2.1) |
| **Type 3** | 1319 | 699 (13.2) | 246 (4.6) | 374 (7.1) | 1325 | 703 (13.3) | 253 (4.8) | 368 (6.9) |
| **TOTAL** | 2240 | 1401 (11.3) | 369 (3.0) | 470 (3.8) | 2252 | 1425 (11.5) | 362 (2.9) | 464 (3.7) |

**Table 4.6 Cot types for matched 2005 and 2006 neonatal units (n=124)**

Looking at the data on the distribution of cots for each type of unit using the matched returns from 2005 and 2006 (Table 4.6) suggests that there appears to have been a streamlining of services, particularly in Type 1 and 3 units, with an increase in special care cots and a decrease in intensive care cots. Overall, this change in the numbers of types of cots means that the unit categorisation changed for 8% (18) of units between 2005 and 2006, with 9 having fewer intensive care cots, and 8 increasing intensive care capacity. These changes in status are among the kind of adjustments anticipated as a consequence of network functioning and re-organisation which the survey has begun to document.

## 4.4. Admissions

In 2005 the reported numbers of admissions to the study units totalled 74510 infants. The unit average was 353 (s.d.170) and ranged from 56-988 infants. As would be expected the number of admissions varied significantly across the three unit types ($p<0.01$) with Type 3 units reporting the highest average number of admissions (Table 4.7).

| Type of Unit | Number of Admissions | | |
|---|---|---|---|
| | Total | Mean (s.d.) | Range |
| **Type 1** | 10669 | 242 (93) | 56-673 |
| **Type 2** | 19641 | 276 (86) | 83-473 |
| **Type 3** | 44200 | 460 (182) | 184-988 |

**Table 4.7 Number of admissions by unit type in 2005 (n=211 neonatal units)**

In the matched units, admissions increased by 1.5% between in 2004 and 2005 (from 41702 to 42310). Table 4.8 shows the regional differences in admission rates and total number of cots in these matched units. In England, Scotland and N.Ireland the number of admissions rose by 280, 321 and 14 respectively.

| Region | 2005 | | | 2006 | | |
|---|---|---|---|---|---|---|
| | Total Admissions | Mean (s.d.) | Number of Cots | Total Admissions | Mean (s.d.) | Number of Cots |
| **England** | 35258 | 339.0 (166.7) | 1865 | 35538 | 341.7 (169.3) | 1887 |
| **Scotland** | 3830 | 425.6 (230.4) | 208 | 4151 | 461.2 (236.9) | 213 |
| **Wales** | 1423 | 203.3 (90.7) | 90 | 1416 | 202.3 (87.7) | 83 |
| **N. Ireland** | 1191 | 297.7 (196.5) | 77 | 1205 | 301.2 (164.7) | 69 |

**Table 4.8 Number of admissions by country in matched units from 2005 and 2006 surveys (n=124)**

Figure 4.1 shows the total number of admissions according to unit type in this matched sample. Admissions in Type 1 units increased by 653 infants while the number of cots increased in these units by 19 over this period.

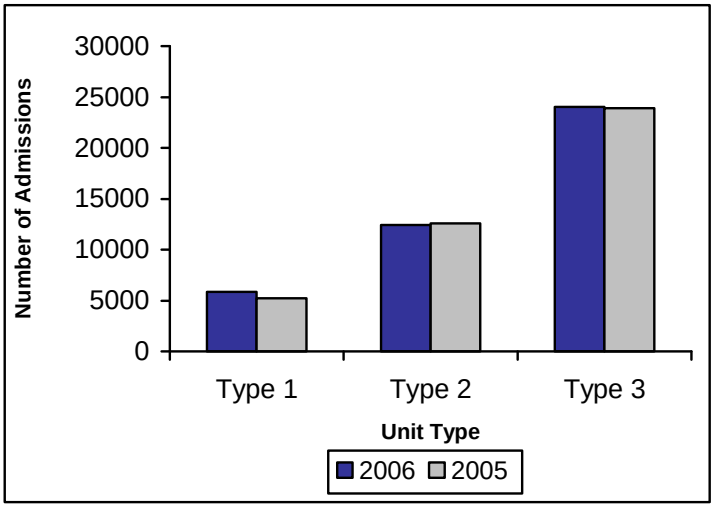


**Figure 4.1 Total number of admissions in matched neonatal units (n= 124 neonatal units)**

### 4.4.1 Admissions by birthweight

Data on admissions in 2005 by birthweight distribution were reported by 157 of the 166 study units. Almost half (n=24795, 49%) of all infants admitted to the study units were low birthweight, 17% (n=8433) were very low birthweight (VLBW) and 6% (n=3240) extremely low birthweight (ELBW). Using the matched 2005/2006 samples it is evident that VLBW admissions increased by 906 babies (5556 to 6462) over this period. In each region the proportion of babies admitted for neonatal care weighing less than 1500g increased by 2%. Northern Ireland had the highest proportion of VLBW admissions (19.2%).

A key aim of networked neonatal services is the provision of access to the appropriate neonatal unit, which means infants are admitted to units able to provide care for the specific

needs of the infants they admit. Although services for many areas in England have been reconfigured, the need for increased intensive care persists as illustrated by Table 4.9 which shows the distribution of admissions according to birthweight for each of the unit types. A total of 7% of all ELBW infants (n=214) were admitted to Type 1 units which did not have designated intensive care cots.

| Birthweight Category | Type of Unit | Number of Admissions | | |
|---|---|---|---|---|
| | | Total | Mean (s.d.) | Range |
| **<1000g** | Type 1 | 214 | 6.9 (5.8) | 0-21 |
| | Type 2 | 648 | 11.6 (10.2) | 0-35 |
| | Type 3 | 2378 | 34.5 (21.8) | 7-107 |
| **1000-1499g** | Type 1 | 578 | 18.1 (12.3) | 2-58 |
| | Type 2 | 1376 | 24.6 (10.2) | 4-45 |
| | Type 3 | 3239 | 46.9 (21.7) | 11-121 |
| **1500-2499g** | Type 1 | 2590 | 80.9 (33.8) | 14-173 |
| | Type 2 | 5184 | 94.2 (32.8) | 22-178 |
| | Type 3 | 8588 | 132.1 (51.4) | 58-323 |
| **>2500g** | Type 1 | 4777 | 154.1 (176.3) | 39-1011 |
| | Type 2 | 7603 | 138.2 (61.1) | 44-322 |
| | Type 3 | 12998 | 200.0 (93.3) | 62-467 |

**Table 4.9 Number of admissions by birthweight in 2005 (n=157 neonatal units)**

### 4.4.2 Unit Capacity and Cot Demands

Despite changes in cot configuration within individual units, almost all those in the study (95%, n=158) reported that, in practice, they commonly exceed their capacity. Little difference was reported in excessive cot demands for intensive compared with high dependency care (Table 4.10). The cot demands which exceed the unit provision for each category of cot grouped according to unit type are also shown. Of note, 56% (19 out of 34) of Type 1 units (with special care and less than 3 high dependency care cots) cared for babies requiring intensive care.

| Unit Type | % (n) units exceeding overall cot numbers | % (n) exceeding SC Cots | % (n) exceeding HD Cots | % (n) exceeding IC Cots |
|---|---|---|---|---|
| **Type 1** | 97 (33) | 79.4 (27) | 64.7 (22) | 55.9 (19) |
| **Type 2** | 87.7 (50) | 63.2 (36) | 68.4 (39) | 59.6 (34) |
| **Type 3** | 100 (75) | 78.7 (59) | 84.0 (63) | 65.3 (49) |
| **Overall** | 95 (158) | 73.5 (122) | 74.7 (124) | 61.4 (102) |

**Table 4.10 Cot demands and unit provision by unit type (n=166 neonatal units)**

Figure 4.2 shows the proportion of units where cot demands exceeded unit provision in the sample of 124 matched units in the 2005 and 2006 surveys.

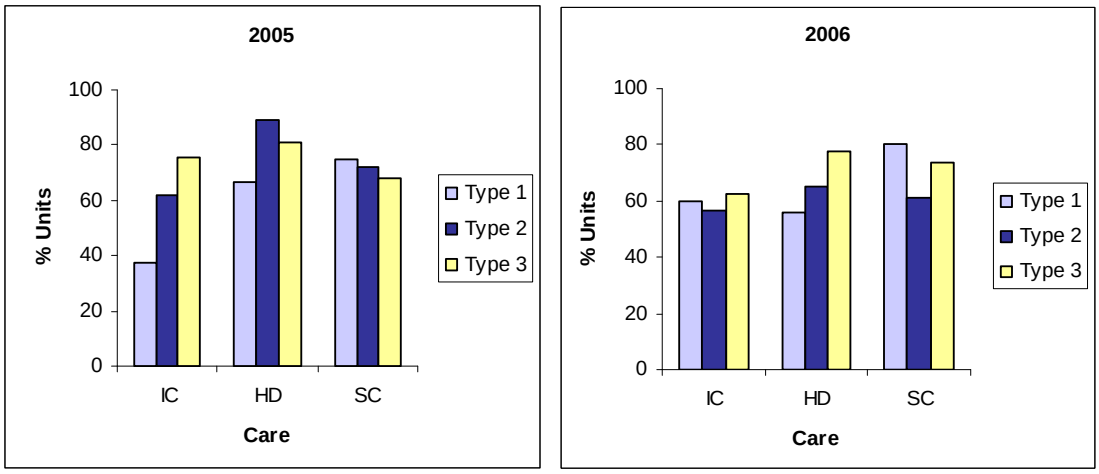


**Figure 4.2 Proportion of matched units where cot demand exceeded cot numbers in 2005 and 2006 (n=124 neonatal units)**

Intensive care demands have almost doubled in small units, which have no intensive care cots, in that the proportion of Type 1 units reporting excessive intensive care demands has risen from 38% to 60%. Conversely, for both Type 2 and 3 units, excessive demands for intensive and high dependency care cots have decreased slightly in this sample.

Based on data from 146 units the average number of days the demands for intensive care exceeded unit capability in the previous six months was 20 (range 0-150). One in ten units had exceeded the demand for intensive care on more than 50 days during this time period, however, there was marked variation (illustrated by the wide range) and the median or midpoint provides a more accurate marker of intensive care demands (Table 4.11).

| Type of Unit | Number of days unit has gone over on Intensive Care | |
|---|---|---|
| | Median | Range |
| **Type 1** | 4 | 0-137 |
| **Type 2** | 3 | 0-93 |
| **Type 3** | 6.5 | 0-150 |
| **Overall** | 5 | 0-150 |

**Table 4.11 Number of days intensive care demands exceeded unit provision in previous six months (n=146 neonatal units)**

### 4.4.3 Cot Bureau

In order to manage transfers and capacity issues half of the study units used a cot bureau, though some used informal, often historical transfer arrangements. Larger units (Type 2 and 3) tended to use such a facility more than small Type 1 units (54% in Type 2 and 3 units compared with 33%).

### 4.4.4 Mechanical Ventilation

Mechanical ventilation is, in the majority of cases, an integral component of intensive care. Most of the study units (80%) could provide data on the number of infants receiving ventilatory support during the previous year. Some provided information about the number of 'ventilator days', but these data could not be used in this analysis. In the 134 study units able to provide ventilator data, on average 100 (s.d. 79) infants per unit received Intermittent Positive Pressure Ventilation (IPPV), Intermittent Mechanical Ventilation (IMV) or Continuous Positive Airways Pressure (CPAP) over the twelve month period. This figure ranged from 7-380 infants. As might be expected, the numbers of infants receiving ventilatory assistance varied significantly across unit type ($p$<0.01) (Table 4.12). A total of 1233 infants were reported to have been ventilated or given CPAP in twenty-eight Type 1 units.

| Type of Unit | Infants receiving assisted ventilation | | |
|---|---|---|---|
| | Total | Mean (s.d.) | Range |
| **Type 1** | 1233 | 44 (62) | 7-328 |
| **Type 2** | 3332 | 69 (42) | 9-208 |
| **Type 3** | 8856 | 153 (78) | 44-380 |

**Table 4.12 Infants receiving IPPV/IMV/CPAP in 2005 (n = 134 neonatal units)**

## 4. 5. Closures

Units may have to close to admissions due to a variety of reasons such as lack of cots or nurses, or infection outbreaks, resulting in infants having to be admitted to alternative hospitals. A total of 77% (n=128) of units reported that they had been closed to admissions one or more times in the previous six months. Closures varied according to unit type, with 59% of Type 1, 75% of Type 2 and 82% of Type 3 units reporting closures in the previous six months (n=20, 43 and 65 respectively). Figure 4.3 shows the proportion of units which had been closed in the previous six months in the 124 matched units responding to the 2005 and 2006 surveys. The proportion of units closing to admissions in 2006 was slightly greater for Type 1 and 3 units compared with 2005.

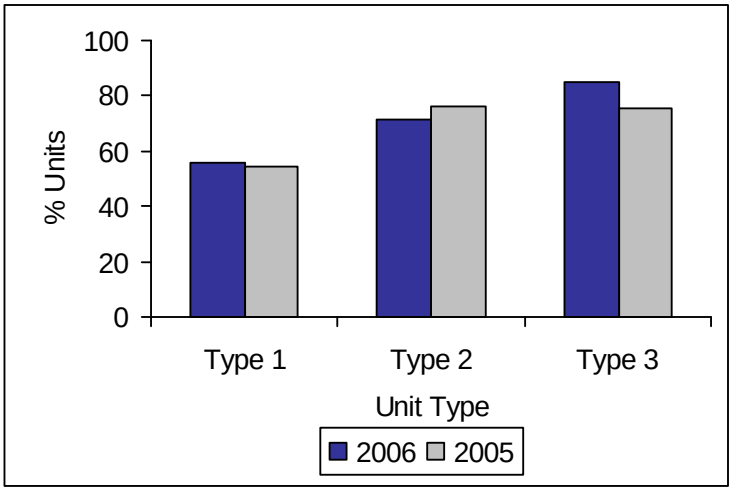


**Figure 4.3 Unit closures in the previous 6 months in matched neonatal units (n=124)**

Of the 128 units which had been closed to admissions, 78% (100) were able to report the total number of days closed in the previous six months. The average was 24 days, though there was considerable variation. Table 4.13 shows the median number of days closed for each unit type.

| Type of Unit | Number of days unit has closed in previous six months | |
|---|---|---|
| | Median | Range |
| **Type 1** | 16 | 2-112 |
| **Type 2** | 10 | 0-103 |
| **Type 3** | 14 | 0-110 |
| **Overall** | 12 | 0-112 |

**Table 4.13 Number of days closed to admissions for different types of unit (n=100)**

## 4.6. Organisational Issues and Capacity

Specific problems arising in relation to unit capacity that were identified by senior unit staff are shown in Figure 4.4. More than two-thirds of units reported problems with nurse staffing. More than a third have difficulties in arranging transfers and a similar proportion in providing care for specific groups of babies, for example those requiring intensive care or babies born at less than 28 weeks gestation.

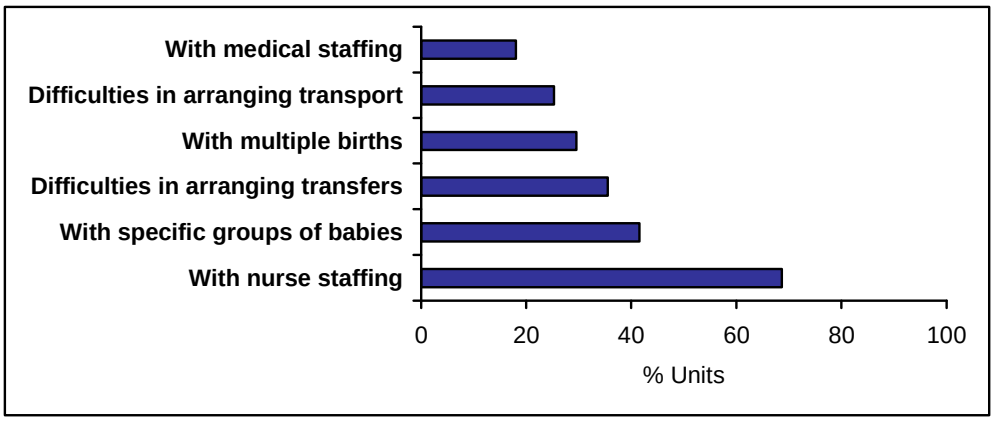


**Figure 4.4 Frequency of factors reported to increase capacity problems (n=166 neonatal units)**

# Section 5: Neonatal unit staffing

For optimal functioning, in parallel with the need for appropriate cots and facilities, neonatal care requires adequate numbers of skilled nurses and doctors.[1] In recognising the importance of staffing issues in relation to the sustainability of neonatal services the DH Review recommended a two-pronged approach[2]:

1) The existing skills and experience should be harnessed

2) Recruitment must keep up with increased neonatal demands.

In particular, it recommended working towards a greater consultant presence in Level 3 units.

## 5.1. Nurse Staffing

### 5.1.1 Current Establishment

Nurse staffing and vacancies, measured in whole time equivalents (WTEs), is shown for the 158 study units who were able to provide such data in Table 5.1. Overall, the total number of WTEs making up the current establishments was 5872.94, with 362.95 WTE (6.2%) vacancies. This equates to a mean nursing establishment for each unit of 37.2 WTE (10-150) with an average vacancy rate of 2.3 WTEs per unit.

| Unit Type | WTEs | | | WTE Vacancies | | | % Vacant of Total WTEs |
|---|---|---|---|---|---|---|---|
| | Total | Mean (s.d.) | Range | Total | Mean (s.d.) | Range | |
| **Type 1** | 537.8 | 16.3 (4.9) | 10.0 - 34.4 | 31.7 | 0.9 (1.2) | 0 - 4.0 | 5.9 |
| **Type 2** | 1387.8 | 24.8 (7.6) | 10.0 - 43.1 | 80.6 | 1.4 (1.7) | 0 - 8.0 | 5.8 |
| **Type 3** | 3937.4 | 57.1 (25.5) | 25.0 - 150.0 | 250.7 | 3.7 (4.8) | 0-24.4 | 6.4 |

**Table 5.1 Whole time equivalents (WTE) and WTE vacancies by unit type (n=158 neonatal units)**

In order to determine how units are staffed in relation to the BAPM and DH guidelines, the recommended nursing establishment (WTE) was calculated for each unit using the following formula:

Establishment = (no. intensive care cots + [no. high dependency cots/2] + [no. special care cots/4] +1) X 5.75

Using this formula, the required unit nursing establishments were calculated for each type of unit. Of the 158 units for which data were available, 6 (3.8%) met the recommended nursing

[1] Hamilton KEStC, Redshaw ME, Tarnow-Mordi W. Nurse staffing in relation to risk-adjusted mortality in neonatal care. *ADC Fetal Neonatal Ed.* Published Online First: 6 November 2006

[2] Department of Health. *Neonatal Intensive Care Review: Strategies for Improvement.* Available at: http://www.neonatal.org.uk/NR/rdonlyres/0AB42821-0B13-4E19-B7A4-612C953154D4/33760/neonatalapr03.pdf

establishment guidelines. The total WTE figures are shown in Table 5.2. Overall, 74% of the nursing establishment recommended was funded for Type 1 units, 65% for Type 2 units and 75% for Type 3 units. The mean numbers of WTEs required and the average mismatch in WTEs for each type of unit are shown in Table 5.3.

| Unit Type | Total Recommended Establishment (WTEs) | Total Current WTE | Total mismatch (WTEs) | Mismatch |
|---|---|---|---|---|
| **Type 1 (n=33)** | 725.94 | 537.76 | -188.18 | 26% |
| **Type 2 (n=56)** | 2149.06 | 1387.84 | -761.22 | 35% |
| **Type 3 (n=65)** | 5272.75 | 3937.42 | -1335.33 | 25% |
| **All units** | 8147.75 | 5863.02 | -2284.73 | 28% |

**Table 5.2 Recommended current total nurse establishment and mismatch for study units (n=158 neonatal units)**

| Unit Type | Recommended WTEs Mean (s.d.) | Match-Mismatch | |
|---|---|---|---|
| | | Mean (s.d.) | Range |
| **Type 1 (n=33)** | 22.0 (4.69) | -5.70 (3.76) | -16.65 to 2.77 |
| **Type 2 (n=56)** | 38.38 (9.14) | -13.59 (5.85) | -32.28 to -0.91 |
| **Type 3 (n=69)** | 76.42 (23.35) | -19.30 (11.85) | -50.02 to 13.90 |
| **All Units** | 51.57 (28.06) | -14.46 (10.13) | -50.02 to 13.90 |

**Table 5.3 Recommended mean nurse establishment and mean mismatch for study units**

Table 5.4 shows the WTE figures for unit type in the matched 2005 and 2006 datasets, indicating an increase in recommended and employed numbers of nurses in each category of unit. Although the mismatch has diminished, the neonatal nursing workforce is still understaffed by 2285 WTEs.

| Unit Type | 2005 | | | 2006 | | |
|---|---|---|---|---|---|---|
| | Recommended WTE | Actual WTE | Mismatch (WTE) | Recommended WTE | Actual WTE | Mismatch (WTE) |
| **Type 1** | 562.12 | 390.39 | -171.73 | 534.75 | 416.49 | -118.26 |
| **Type 2** | 1597.12 | 1043.34 | -553.78 | 1768.13 | 1132.94 | -635.19 |
| **Type 3** | 3858.32 | 2776.52 | -1081.79 | 3933.00 | 2958.38 | -974.62 |

**Table 5.4 Recommended total nurse establishment and mismatch for matched units (n=119 units)**

### 5.1.2 Nurse Staffing and Network Changes

Data were collected about any changes made to nurse staffing following the introduction of neonatal networks in England. Approximately 1 in 5 units (22%) had made some changes. Most of these were on a small scale and for all but one unit involved increases in nursing establishment. More nurses and nursery nurses were employed in Type 1 units and more neonatal nurses and practice development or facilitator staff were employed in Type 2 units. In Type 3 units the changes were more diverse and a range of additional staff at different points on the skill mix continuum were employed in different units: neonatal nurses, midwives, neonatal nurse practitioners, nurse educators, clinical support workers, and staff specifically employed for working in transitional care.

Survey respondents were also asked about any future changes planned in nurse staffing for neonatal care. For a total of 60% of units changes in nurse staffing as a consequence of networks were a possibility. Among the Type 1 units were several where closure was considered likely, others expected an increase in nursing staff and one mentioned rotation of staff across units. The uncertainty of their situation was also reflected in the Type 2 unit responses: reconfiguration of services was ongoing, resulting in a lack of clarity about unit status; one unit referred to closure, another to a merger; some mentioned staff rotating or working in more than one unit, many mentioned an increase in staffing numbers, with two referring to network funded posts and another indicated that there were plans to develop transitional care facilities. For many Type 3 units where change was anticipated, this was in terms of increased numbers of neonatal nursing posts. Less commonly, units were looking at increasing or introducing nursery nurses and support workers to be employed within the unit; shared posts across more than one unit and the involvement of neonatal nurse practitioners in the developing transport services. For some the unresolved issue of reconfiguration was clearly affecting their future planning, with concerns about funding, closure, changes in status and possible staff losses consequent on that.

### 5.1.3 Skill Mix

The proportions of nursing staff by title in the different types of unit were generally similar and are shown in Figure 5.1. The core group in the neonatal nursing workforce is clearly staff-nurses and staff midwives, followed by sisters and charge nurses and then health care assistants and nursery nurses, with little difference between the different types of unit.

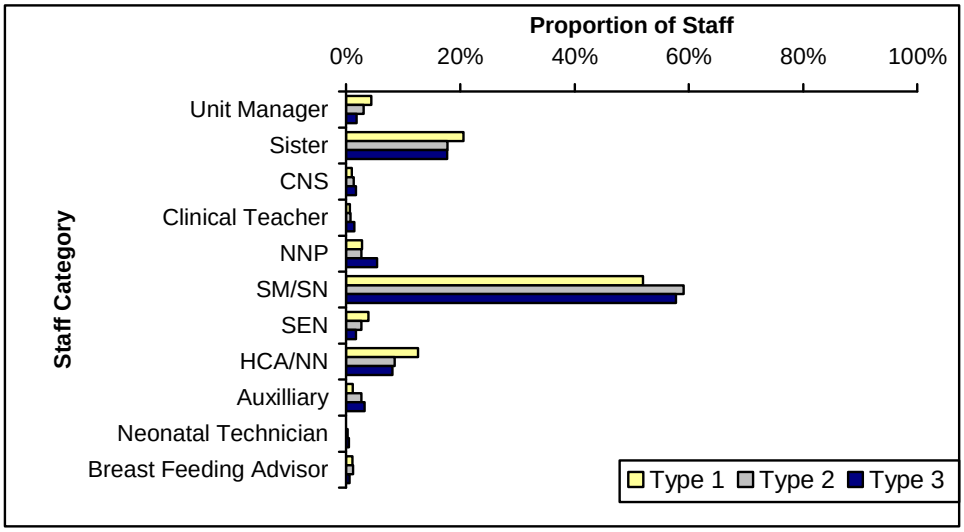


**Figure 5.1 Distribution of nursing staff by job title and unit type (n=162 units)**

Being qualified in the specialty (QIS) involves obtaining a post registration specialist qualification in neonatal nursing. In the 136 units for which data were made available a total of 56% of nursing, midwifery and related staff working in the study units and having direct contact with babies had a neonatal qualification. If the QIS group considered just includes trained midwifery and nursing staff the figure increases to 62%. The proportions of the different staff groups qualified in this way are shown in Table 5.5.

| Staff Category | % (n) With neonatal qualification | | | |
|---|---|---|---|---|
| | Type 1 | Type 2 | Type 3 | Overall |
| **Sister/ Charge Nurse** | 70.3 (88) | 82.9 (270) | 82.1 (636) | 81.1 (994) |
| **Clinical Nurse Specialist** | 100 (6) | 100 (24) | 100 (74) | 100 (104) |
| **Neonatal Nurse Practitioner** | 100 (17) | 100 (50) | 100 (210) | 100 (277) |
| **Staff Midwife /Staff Nurse** | 42.8 (136) | 36.6 (399) | 58.4 (1495) | 51.2 (2030) |
| **SEN** | 8.5 (2) | 53.3 (26) | 11.9 (9) | 25.1 (37) |

**Table 5.5 Proportion of nursing staff qualified in speciality by unit type (n=136 neonatal units)**

## 5.2. Medical Staffing

Medical staffing is arranged in a variety of ways across units and has particularly as a consequence of the European Working Time Directives. Basic information about the numbers of medical staff involved in neonatal care in the different types of unit is shown in Table 5.7. Although in some neonatal units, neonatal nurse practitioners are included on medical staffing rotas, they are not included in the table.

| Medical Staff | Type 1 | Type 2 | Type 3 |
|---|---|---|---|
| | Mean (s.d.) | Mean (s.d.) | Mean (s.d.) |
| **Neonatologists** | 0.3 (1.1) | 0.5 (1.0) | 3.2 (2.2) |
| **Paediatricians** | 4.7 (1.4) | 5.0 (1.7) | 3.0 (3.2) |
| **Staff Grades** | 1.9 (1.5) | 1.7 (1.6) | 0.7 (0.9) |
| **Specialist Registrar** | 1.9 (2.3) | 3.6 (2.3) | 5.2 (2.8) |
| **SHOs** | 5.9 (3.3) | 6.4 (3.2) | 7.3 (3.2) |

**Table 5.6 Number of medical staff currently employed (165 neonatal units)**

Currently 39% of consultants have 50% or more of their clinical sessions dedicated to neonatal care, a slight increase from last years figure of 36%. As expected, the greatest consultant input is in the Type 3 units with 67% of consultants having 50% or more of their sessions in neonatal care, compared with 26% in Type 2 and 11% in Type 1 units.

Many more consultants contribute to the on-call rota for neonatal care in an individual unit: overall 92% of consultants contribute to the emergency rota. A slightly higher proportion of consultants contribute to the neonatal on-call rota in the more intermediate Type 2 units, 95%, as compared to 92% in Type 3 and 87% in Type 1 units.

### 5.2.1 Medical Staffing and Network Changes

As with nurse staffing, data were also collected about possible future changes in medical staffing consequent to the introduction of networks. Nearly half the responding units in England anticipated changes in medical staffing (44%). For one Type 1 unit loss of training posts was expected, for another a new consultant neonatologist post was seen as likely and others mentioned changes associated with the reconfiguration of obstetric and neonatal cover. Type 2 units largely referred to having more and better cover, more consultant posts and more neonatologists. Changes were planned to rotas and individual posts, with more sessions dedicated to neonatal care, though one unit mentioned the possible loss of a consultant post with reconfiguration. Respondents in Type 3 units focused on the provision of more consultants, more consultant neonatal posts and some on more medical staff across all grades. Less commonly they referred to joint posts, rotation across units to maintain skills, an increase in neonatal nurse practitioner posts and additional staff with a remit for transport.

# Section 6: Neonatal Transport

Transport of neonates is a priority area in the delivery of neonatal services, particularly as the aim of networked care is to offer families access to appropriate care as close to home as possible while reducing unnecessary transfers to units further away from home for intensive care. A recent ten year review of neonatal transport services shows that alongside rising intensive care activity during the past 10 years, the number of 'inappropriate transfers' remained persistently high.[1]

## 6.1 Unit Transfers

The most common reasons for babies being transferred between neonatal units are shown in Tables 6.1 and 6.2. While individual data on the population of babies transferred would provide more accurate information, the extent to which such data are collected systematically is highly variable and the availability of such information limited. The data collected thus provide a broad picture of the most common reasons for transfer. The data are shown by unit type as this is the most meaningful way to understand the link between this aspect of care provision and organization. The key issues relate to the need for specialised services and for intensive care, adequate capacity and staffing and the need to match the needs of babies with the kind of care provided in the different types of unit.

| **Reasons for infants being transferred OUT** | **Unit type %** | | | |
|---|---|---|---|---|
| | **Type 1** | **Type 2** | **Type 3** | **All Units** |
| **Babies requiring specialist services (e.g. ECMO, Nitrous Oxide) or surgery (including cardiac)** | 82.1 | 90.0 | 76.4 | 82.5 |
| **Babies requiring neonatal intensive care (includes ventilation for other than short term)** | 89.3 | 51.7 | 16.7 | 42.5 |
| **Preterm babies (extremely preterm, with cut-offs, e.g. < 26 weeks, < 28 weeks)** | 28.6 | 43.3 | 6.9 | 24.4 |
| **Shortage of staff** | 7.1 | 6.7 | 12.5 | 9.4 |
| **Capacity (includes unit closed, cots full)** | 14.3 | 20.0 | 40.3 | 28.1 |
| **Freeing up intensive care/high dependency cots** | 3.6 | 3.3 | 5.6 | 3.1 |
| **Proximity to parents' home** | 0.0 | 3.3 | 5.6 | 3.8 |
| **Back transfer for continuing care** (includes babies originally transferred in utero and then admitted to NNU) | 0.0 | 18.3 | 45.8 | 27.5 |

**Table 6.1 Most common reasons for transfers out of target neonatal units (n=160 units)**

[1] Cusack JM, Field DJ, and Manktelow BN. The impact of service changes on neonatal transfer patterns over 10 years. *ADC Fetal Neonatal Ed*. Published Online First: 9 November 2006.

For Type 1 units the most common reason for transfers out was the need for specialist services not provided locally. Transfers out of Type 2 units are also dominated by the need for specialist services, but in addition may be a function of the type of babies that the unit is not able to care for, with cut-offs in gestation often agreed within the network. While transfers out of Type 3 units may also be for specialist services, a common reason is their own lack of capacity at the time of transfer. Many of their transfers out will also be back transfers to a local unit.

Some reasons for transfers into Type 1 units related to the capacity of transferring units, but more commonly to back transfers following delivery or higher level care of local babies elsewhere. The picture is similar for Type 2 units, though more reported transfers in as consequence of capacity problems in the transferring unit. Type 3 units were most likely to receive babies requiring the specialist or intensive care that they could provide, but also because of capacity issues in the transferring units.

| **Reasons for infants being transferred IN** | **Unit Type %** | | | |
|---|---|---|---|---|
| | **Type 1** | **Type 2** | **Type 3** | **All Units** |
| **For specialist services (e.g. ECMO, Nitrous Oxide) or surgery (including cardiac)** | 3.1 | 3.4 | 33.3 | 17.2 |
| **For neonatal intensive care (includes ventilation for other than short term)** | 3.7 | 6.9 | 47.2 | 24.8 |
| **Preterm babies (extremely preterm, with cut-offs, eg < 26, < 28 weeks)** | 7.4 | 1.7 | 22.2 | 12.1 |
| **Shortage of staff in the unit transferring out** | 0.0 | 1.7 | 5.6 | 3.2 |
| **Capacity of the unit transferring out (includes unit closed, cots full)** | 25.9 | 46.6 | 48.6 | 43.4 |
| **Freeing up intensive care/high dependency cots in transferring unit** | 7.4 | 13.8 | 8.3 | 10.2 |
| **Proximity to parents' home** | 11.1 | 8.3 | 5.6 | 8.3 |
| **Back transfer for continuing care** | 44.4 | 39.7 | 22.2 | 32.5 |
| **Transfer to hospital in which originally booked** (after in utero transfer and care in another unit) | 35.7 | 20.7 | 8.3 | 17.8 |
| **For continuing care in high dependency or special care** | 35.7 | 23.6 | 6.9 | 20.4 |
| **Babies from the community or needing re-admission for neonatal care** | 7.4 | 3.4 | 0.0 | 2.6 |

**Table 6.2 The most common reasons for transfers into target neonatal units (n=157 units)**

Distance data for transfers in and out of neonatal units are shown in Table 6.3. While the figures shown relate to the furthest distances that babies had been recently transferred, and not the average distance, the data are presented to indicate the upper boundaries in terms of the distances that babies and families may have to travel.

| Unit Type | Mean farthest distance (miles) | Median | s.d. | Range |
|---|---|---|---|---|
| **Type 1** | 67.26 | 60 | 35 | 12-138 |
| **Type 2** | 74.34 | 64 | 55 | 1-250 |
| **Type 3** | 103.5 | 80 | 101 | 6-540 |

**Table 6.3 Furthest distance a baby was transferred out in the previous six months from the different types of neonatal unit. (n=145 units)**

## 6.2 Network Transport

> 'Transport issues are our biggest problem. Recurrent funding is insufficient to provide a vehicle and driver plus a medical and nursing team'

Half of the 22 network managers reported that transport arrangements had changed with the introduction of the network. Six networks currently have a network-wide transport service with another three actively in the process of setting up a service. Transport is co-ordinated in a wide variety of ways: one network has a 24 hour hotline service, five have a daytime service via either a hotline to the Level 3 centre, the East of England Transport Service or the Neonatal Transport Service. The remaining networks currently operate using ad hoc arrangements.

Five networks were able to provide transfer numbers. In these networks, 458 babies were transferred out of the network during 2005 (average 92 babies per network). The farthest distance that these babies were transferred out ranged between 70-486 miles, equating to an average farthest distance of 187 miles. The most common reasons for transfer outside the network are shown in Figure 6.1. The need for specialist services and cot availability predominate.

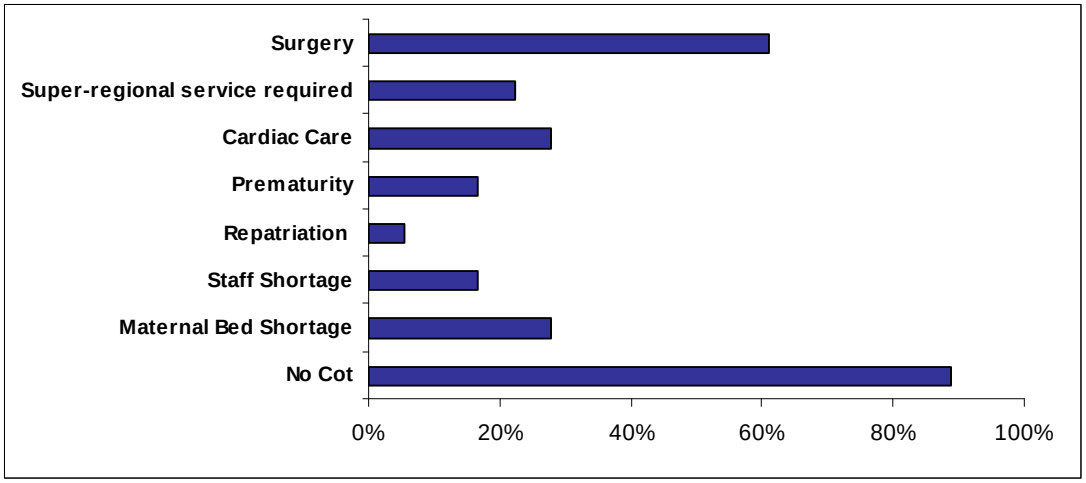


**Figure 6.1 Reasons for transfer out of neonatal network (n=22 networks)**

The majority of networks were unable to provide figures or details of transfers into the network. In future however, with the introduction and use of neonatal audit systems by individual units and data compiled for and by networks, it is likely that the data on transfers will be available.

The most common reasons for transfers into the network given by network managers are shown in Figure 6.2. Cot availability dominates the list.

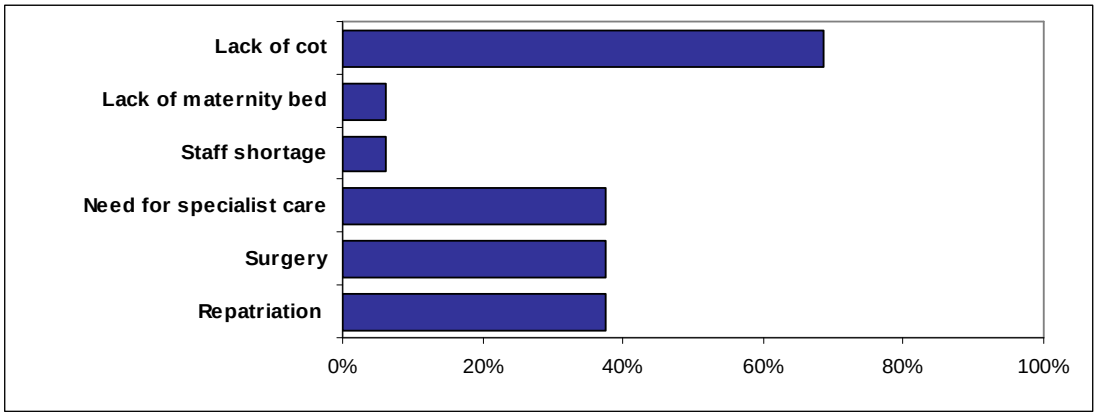


**Figure 6.2 Most common reasons for transfer into neonatal network (n=22 networks)**

In general, it seems that the reasons for transfer between networks were generally similar to those between units, with capacity issues and the need for specialist services predominating.

# Section 7: The parents' perspective

The focus of the 2006 survey of parent experience was on admission, transfers before and after birth, care in the unit and travel as experienced by parents whose baby has been cared for in one or more neonatal units.

## 7.1 The parents who participated

A total of 406 parents whose baby had been in a neonatal unit completed a web-based survey between March and July 2006, of whom 356 had a baby admitted in the last two years. The data presented in this report are based on this group of 356 parents and families. Not every parent responded to every item and the numbers on which the proportions are based are shown in each table.

| | | % |
|---|---|---|
| **Respondents** | Mothers | 91.4 |
| | Fathers | 3.8 |
| | Both parents | 4.3 |
| | Other | 0.6 |
| **Age group** | <20 years | 1.7 |
| | 20-25 | 16.6 |
| | 26-30 | 26.1 |
| | 31-35 | 36.1 |
| | 36-40 | 5.8 |

**Table 7.1 Survey respondents (n=356)**

The respondents were almost all mothers (Table 7.1), with more than half in their late twenties and early thirties (Table 7.2). In terms of ethnicity, most were white (97%). For over half (62%) this was their first baby. A total of 9% of responding parents had experience with a previous baby admitted in NNU.

### 7.1.1 Characteristics of babies

Most of the babies were singletons though, as is common in neonatal care, quite a large proportion were born as twins or triplets (18%) (Table 7.2).

| Parents | % |
|---|---|
| 287 | 80.6 singletons |
| 64 | 18.0 twins |
| 5 | 1.4 triplets |

**Table 7.2 Multiplicity of babies admitted (n=356 births)**

As might be expected a large proportion (94%), of the respondents' babies were born preterm (at less than 37 weeks). The distribution for gestational age at birth is shown in Figure 7.1 and the details in Table 7.3. The average gestational age at which babies were born was 30 weeks.

| (n= 345) | Gestational Age |
|---|---|
| Mean (weeks) | 29.96 |
| s.d. | 3.68 |
| range | 23-42 |
| median | 30 |

**Table 7.3 Gestational age of babies (n=345)**

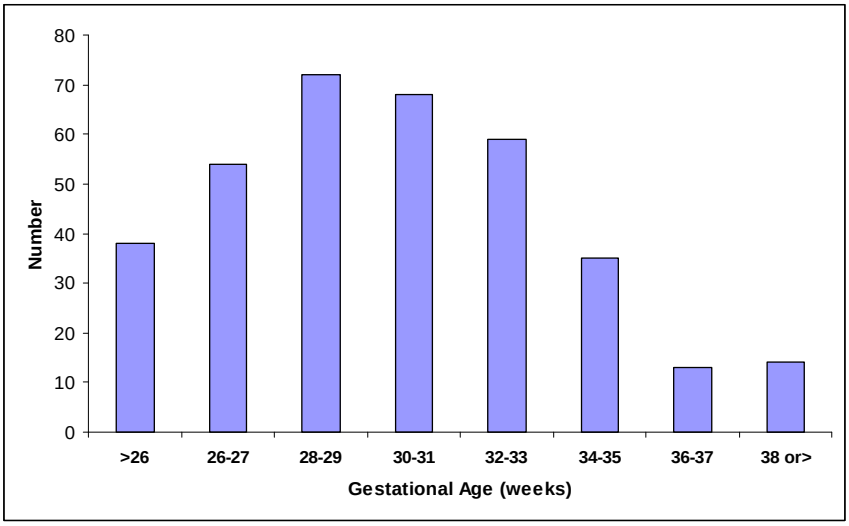


**Figure 7.1 Distribution of babies by gestational age (n=346)**

The most common reason given by parents for admission to neonatal care was preterm birth (93%). However, babies were also admitted because of intra-uterine growth retardation, congenital abnormalities, infection and following events in delivery, such as cord prolapse or placental abruption. A total of 93% were low birth weight (less than 2500 g. at birth) and 61% were extremely low birth weight (less than 1500 g.)

With prematurity, low birthweight and the kind of health problems mentioned it is not surprising the babies of the respondents in the survey had relatively long stays in hospital with an average of nearly two months (Table 7.4). During their stay a large proportion of babies had respiratory problems requiring ventilatory assistance, with 76% being ventilated or on CPAP, some for quite long periods (mean 25.77 days, median 10 days).

| *Duration of stay in hospital (total days) (n=331)* | |
|---|---|
| Mean (sd) | *55.05 (37.2)* |
| Median | *48* |
| *Range* | *2-196* |

**Table 7.4 Length of stay in neonatal care (n=331 babies)**

## 7.2. The possibility of neonatal care

### 7.1.2 Maternal admissions

A large proportion of mothers responding to the survey whose babies later required neonatal care experienced antenatal stays in hospital (57%). When there was concern about their pregnancy and health the mothers in the survey were admitted for periods ranging from 1-90 nights, with an average of 10.22 nights (median 6.5). The reasons for these admissions included hyperemesis (severe vomiting), high blood pressure and pre-eclampsia, bleeding, premature rupture of membranes and threatened preterm labour, placenta praevia and intra-uterine growth retardation. The kind of conditions necessitating care in hospital raise serious concerns about the health and wellbeing of pregnant women and their babies and the anxiety associated with them may affect their wellbeing and that of their families.

### 7.1.3 Awareness of the need for neonatal care

Perhaps partly as a consequence of these admissions to hospital, just over a third of the women (35%) became aware during their pregnancy that their baby would require admission to a neonatal unit. In contrast, a larger proportion may have had relatively little time to adjust as over half of the respondents only became aware in the course of labour and birth or shortly afterwards (62%) that their baby would need care in a neonatal unit. A smaller proportion of babies (4%) were admitted after being on the postnatal ward.

Parents were asked if before the birth they had understood there was a possibility that their baby might have to be transferred for neonatal care at another hospital. A total of 35% were aware that this might happen. They were also asked if they were aware before their baby was born that care for infants like theirs is organised in ‘Neonatal Networks’. A much smaller proportion (15%) were aware that neonatal care was now organised in this way.

## 7.3 Transfers

### 7.2.1 Antenatal Transfers

Approximately a third of the women surveyed (32%) were transferred between hospitals just before or during their labour, and just under a quarter (23%) between hospitals (Table 7.5).

| ***Transfers*** | |
|---|---|
| From one hospital to another | *80 (71.4%)* |
| From a separate midwifery-led unit to hospital | *3 (2.7%)* |
| From one part of the hospital to another | *26 (23.2%)* |
| *From home to hospital* | *3 (2.7%)* |

**Table 7.5 Transfers just before or during labour (n=112 mothers)**

The respondents were also asked about the reasons for transfer (Table 7.6) and some gave more than one reason. A number of factors seemed to be in operation: a mother might be ill, her baby likely to need specialist facilities and an intensive care cot might not be available in the area or hospital where the mother was in labour or likely to go into labour.

| **Reasons** | ***% (n) of transfers*** |
|---|---|
| Staff were concerned about the baby | *28.6 (32)* |
| I was ill | *13.4 (15)* |
| I needed specialist facilities available elsewhere | *17.9 (20)* |
| My baby was likely to need specialist facilities elsewhere | *52.7 (59)* |
| No intensive care cots were available | *42.0 (47)* |
| *Other* | *10.1 (12)* |

**Table 7.6 Reasons for mothers being transferred just before or during labour (n=112 mothers)**

Respondents' comments in relation to transfer at this time related to gestational age cut-offs for care and capacity:

> *'I was transferred to Hospital X whilst I was pre 28 weeks as Hospital Y were unable to deal with babies before 28 weeks. At 28 weeks I was transferred back to Hospital X and gave birth 3 days later.'*
>
> *'The hospital I was at only took babies from 32 weeks not 29, so I was transferred to another hospital before I had him.'*
>
> *'I was transferred in labour from my local hospital to one 2 hours away, then 2 days later the NICU cot had gone there so I was transferred in full labour 20 mins down the road to the next hospital with a NICU cot.'*
>
> *'An intensive care place was required by another lady, the transfer was to another local hospital'*

'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 bay was 7 days old'

### 7.3.2 Postnatal Transfers

Over a third (35%) of respondents indicated that one or more of their babies were transferred from one hospital to another after the birth. The timing of the transfer varied, with a quarter of the babies who were transferred being moved on the first day of life and just over half within the first week of life (Table 7.7).

| Timing of first transfer | % Babies transferred |
|---|---|
| One day or less of age | 25 |
| 2-7 days | 26 |
| 8-14 | 16 |
| 15-30 | 11 |
| >30 days | 22 |

**Table 7.7 Timing of transfer after birth (n=100 babies)**

The numbers of transfers that babies and their families experienced is shown in Table 7.8. While the majority of those transferred were only moved once, a quarter of those moved were transferred twice or more. Most of the babies who were transferred a number of times were moved backwards and forwards between just two hospitals, however a small proportion (4%) were cared for in three or more different hospitals.

| Transfers | % (n) respondents |
|---|---|
| Baby transferred once | 28.0 (94) |
| Baby transferred twice | 6.5 (23) |
| Baby transferred three times | 1.1 (4) |
| Baby transferred four times | 1.1 (4) |
| Baby stayed in one unit only (not transferred) | 64.9 (231) |

**Table 7.8 Numbers of transfers experienced by babies in neonatal care (n=356)**

Parents were asked about the reasons for transfer (Table 7.9). While cot availability was an issue for some families, especially those with babies requiring intensive care, infants needing specialist care or else returning to the local unit towards the end of the period of hospitalisation following delivery were more commonly transferred.

| Reasons for transfer | n (%) transfers |
|---|---|
| Baby needed specialist care available elsewhere | 50 (40.0) |
| An intensive care cot was not available | 17 (13.6) |
| A special care cot was not available | 3 (2.4) |
| To go back to local unit | 57 (45.6) |
| Other | 16 (12.8) |

**Table 7.9 Parents' views of the reasons for transfer of their babies (n=125)**

The predominant reasons that parents reported for infant transfer were because specialist care was needed that was not available locally at the unit in which they had been born or where they were being cared for; or that they were being returned to their local unit. In the immediate post-birth period capacity was sometimes an issue and while most of the twins and triplets were cared for in the same hospital, nearly a quarter (9/38) were looked after in different neonatal units. Half of the babies moved at one day of age or less were transferred because no intensive care neonatal cots were available in the hospital where the baby was born. Other transfers took place when babies required specialist surgery or other treatment.

Among the respondents' additional comments about the reasons for their baby being transferred, some of which were similar to those raised in relation to antenatal transfers e.g. gestational age criteria:

> *'They told me they didn't deal with babies of 28 weeks.'*
>
> *'My baby was born at Hospital X, but later that day was transferred to Hospital Y as Hospital X do not take babies under 28 weeks.'*
>
> *'The hospital my baby was born in dealt with babies born at 28 weeks onwards, not 25 weeks'*
>
> *'The hospital we were initially admitted to couldn't accommodate babies under 32 weeks'*

The other related to capacity:

> *'Staff shortages and intensive care bed shortages'*
>
> *'The twins were separated and transferred to separate towns due to no hospitals having two beds'*
>
> *'We were put under lots of pressure to be transferred back to our admitting hospital, all the time during our twins stay'*

Parents' expectations and experience in relation to transfer varied considerably (Table 7.10). Some were relieved that their baby did not have to be moved to another hospital, though this had been anticipated (16%) and for others it was a surprise or shock (13%).

| Expectations and actual transfers | % (n) respondents |
|---|---|
| Did not expect baby to be transferred + baby was not transferred | 49.6 (169) |
| Transfer was possible antenatally + did not take place | 21.7 (74) |
| Transfer was possible antenatally and baby was transferred | 15.8 (54) |
| Transfer was not expected antenatally and did take place | 12.9 (44) |

**Table 7.10 Antenatal expectations and actual transfers of babies for neonatal care (n=341)**

For the transfers reported, a quarter of parents (25%) indicated that their baby (or babies) was transferred within the same network, 11% that the move had taken place outside the network and the remainder, the majority of parents whose baby had been moved (64%), did not know if the unit to which their baby had been transferred was within the local network or not.

Parents were asked about specific aspects of the transport process (Table 7.11) and while many were informed about the transfer of their baby, not all experienced this; one third indicated that they were not introduced to the transport team and a similar proportion were not given information about the neonatal unit to which their baby was being moved. A smaller proportion indicated that they did not have the transport arrangements explained to them.

| Aspects of Transport | Yes % | No % | Not sure/ don't know |
|---|---|---|---|
| Mother was well enough to go at the same time as the baby was transferred | 82.1 | 12.8 | 5.1 |
| The transport arrangements were explained | 81.2 | 14.5 | 6.0 |
| Arrangements were made for parents to travel at the same time as their baby | 21.4 | 72.6 | 5.0 |
| Introduced to the transport team | 65.8 | 33.3 | 1.0 |
| Given information about the NNU to which the baby was transferred | 63.3 | 31.6 | 5.1 |

**Table 7.11 Aspects of transport affecting parents (n=117 transfers)**

### 7.3.3 What concerned parents about transfers

Those parents whose baby or babies had been transferred were asked if they had any issues or concerns about their baby's transfer. Their own words reflect the uncertainty, need to be informed and the impact that distance and unfamiliarity have on parents who are already under stress:

> *'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.'*

*'The distance. 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.'*

*'I was very scared as I had to find my own way to the hospital and didn't know how my baby was coping with the journey, but all the transport team were very friendly and supportive and explained everything that would happen to me.'*

*'Only that I was unsure what surroundings she would be going to, it was an unfamiliar place after being amongst people I knew.'*

*'I did not want my baby to be moved as he was still on CPAP and the unit he was being moved to did not have the same equipment and specialist service.'*

*'Both myself and my partner were concerned about our daughter making the 2 hour journey but at the same time we knew that she was in safe hands'*

The practical difficulties associated with transfer for both parents and staff are substantial:

*'The hospital was 120 miles away, no date was given for her transfer back and the unit kept fobbing us off, putting the transfer back because they couldn't spare any staff. For example we'd ring in the morning to find out if she'd be transferred that day and they'd say yes, about 11, or whatever, so we wouldn't set out, thinking we'd see her late afternoon when she'd get back to our local hospital, then we'd ring our local hospital about two to see if she'd been arrived and they'd say 'oh, it's put off till tomorrow' with us faced with a 5 hour round trip and nowhere to stay. This happened at least 3 times leaving us sad, frustrated, powerless and disappointed.'*

*'They told me that he was being transferred back to our local hospital half an hour before he went... I was told Id have to make my own way home, and we were over 120 miles away from home... I had no money, so had to wait for family to drive up and collect me...my baby was already settled in NICU in local hospital by time I got there 7 hours later.'*

*'Because he was transferred by ambulance, which was also being used for emergencies, so the hospital were unable to tell us when he would be moved. They didn't know which day or what time, which left us feeling very unsure about visiting him. It was also disappointing that we could not travel with him or even be there when he arrived.'*

The situation for mothers who themselves have been ill is even more difficult when their babies are transferred:

*'I was concerned I wouldn't get to see my baby as I was so poorly at the time, but I remember the transfer team being really nice and they brought the transfer incubator to my bed before they left. Also I remember being told that the unit she was going to was excellent so I was confident that she would be well looked after, but I hated her having to be taken away.'*

### 7.4 Care In The Neonatal Unit

The parents responding to the survey experienced neonatal care differently (Table 7.12). It is not easy being a parent in a neonatal unit and some felt that staff were critical, did not always feel able to stay by their baby as long as they wished or feel included in the care of their baby.

| When visiting your baby did you? | Always | Sometimes | Never |
|---|---|---|---|
| Feel able to sit by your baby as long as you wanted (n=349) | 67.9 | 28.9 | 3.3 |
| Feel you could have the people visit that you wanted (n=349) | 42.1 | 45.0 | 12.9 |
| Have skin to skin contact with your baby (n=347) | 30.8 | 44.7 | 24.5 |
| Sometimes feel that you were in the way (n=347) | 8.1 | 50.7 | 41.2 |
| Find feed times flexible enough (n=335) | 53.4 | 38.2 | 8.4 |
| Find that the staff were aware of parents needs (n=346) | 52.0 | 43.6 | 4.3 |
| Feel that staff were critical (n=345) | 13.6 | 38.0 | 48.4 |
| Feel included in your baby's care (n=345) | 62.0 | 31.9 | 6.1 |

**Table 7.12 Needs and experiences of parents with babies in neonatal care**

In the open-ended text responses, while many described experiencing 'exemplary' care, at the same time they also contrasted care in different hospitals and between staff. Parents also identified a need for continuing psychosocial support both in and after leaving the unit. Overnight accommodation is critical when babies are very sick or parents are coming from a long distance. A total of 55% of parents used the accommodation and of this group nearly three-quarters (73%) indicated that this was for as long as they needed (Table 7.13).

| Facilities | % Yes | % No | % Don't know |
|---|---|---|---|
| Accommodation in for mothers in/ next to the unit | 64.2 | 24.6 | 10.4 |
| Accommodation in for both parent in / next to the unit | 48.4 | 36.8 | 14.8 |

**Table 7.13 The availability of accommodation for parents (n=345)**

Parents were asked some factual questions about the sources and type of information available to them (Tables 7.14 and 7.15).

| Frequency | The equipment and procedures explained to you (n=342) % | Your baby's problems discussed with you (n=346) % |
|---|---|---|
| Always | 70.8 | 72.0 |
| Sometimes | 25.4 | 25.1 |
| Rarely/Never | 3.8 | 2.9 |

**Table 7.14 Verbal information provided for parents with a baby in neonatal care**

While more than 70% of respondent parents reported that they had always been given explanations about the technical aspect of their baby's care and that their baby's medical problems had been discussed with them, this was not always the case for a quarter of parents and a very small proportion felt that neither of these things had occurred.

| Written sources of information | (%) |
|---|---|
| Neonatal Unit written information | 78.4 |
| BLISS written information | 61.7 |

**Table 7.15 Written information for parents with a baby in neonatal care (n=347)**

Many parents were given information in a written form from the individual neonatal units in which their babies were resident. However, more than one in ten (13%) reported receiving no written information, either written by the neonatal unit staff or supplied by BLISS.

Parents were also asked about the advice they would give to other parents whose baby had just been admitted or transferred to a neonatal unit. The need to seek information was identified by many of the respondents, despite the fear and anxiety they had experienced:

> *'Don't be afraid to keep asking the same questions over and over again. As you are so worried about your baby, it takes a while and several explanations before information sinks in.'*
>
> *'Never be afraid to ask questions and to get clarification on anything that you don't understand. Remember it's YOUR baby, don't be afraid to question any care that you don't feel happy about or are unsure of.'*
>
> *'Don't be afraid to ask questions and advice from the staff. Try to write them down as you think of them when you are at home as you may forget them when you are in the unit.'*
>
> *'Take one day at a time and don't feel afraid to ask as many questions as you need to. Find out if there's a 'welfare officer' on the unit who should be able to give you lots of practical advice…… Expect to feel upset and confused by what is going on - gradually the SCBU will become more familiar depending how long your baby is there. Keep a diary... It will help you realise that your baby is (hopefully) making progress even if sometimes it doesn't feel like it.'*

### 7.4.1 Getting to the unit

Parents were asked about the distance travelled to see their baby, and for those with a baby in more than one unit they were asked to indicate the longest travel distance (Table 7.16).

| Travel distance | % respondents |
|---|---|
| One mile or less | 8.7 |
| 1-5 miles | 28.6 |
| 6-10 miles | 21.0 |
| 11-30 miles | 29.7 |
| 31-50 miles | 5.5 |
| > 50 miles | 6.4 |

**Table 7.16 Distance travelled by parents (n=343)**

A total of 12% of families travelled more than 30 miles in order to see their baby.

| Daily travel cost in pounds (£) for you and/or your partner to see your baby in the neonatal unit | |
|---|---|
| 6.44 (6.83) | Mean (s.d.) |
| 1- 60 | Range |
| 5.00 | Median |

**Table 7.17 Costs of travel for parents (n=297)**

Parents were also asked to give an estimate of daily travel costs and the cost of parking. More than half (54%) had to pay for parking, for which the cost ranged from 50p-£25, with a mean of £3.40 (median £2.00, range £0.50-25.00). There was practical advice from parents in relation to visiting and parking:

> *'Find out about weekly parking tickets for 'long termers' we paid a daily rate until someone told us about a weekly ticket.'*

> *'Buy parking permit if you visit during day as it is much cheaper. I used to visit in evenings only so parking was free and also wasn't in the way of doctors and staff.'*

> *'Ask if you are entitled to free parking, this information doesn't seem to be handed to you on a plate.'*

> *'Take food as buying from the canteen for two people three times daily costs around £150 per week.'*

> *'Most important, try to take some time out every now and then, I ended up making myself ill travelling to the hospital four times a day.'*

## 7.5 Wider Issues for Parents

A multiplicity of issues were raised by many respondents, many in the form of advice to other parents:

> *'Resources and spending in this area of the NHS is dangerously low and needs to be given higher priority. Parents practical issues are also ignored, including accommodation close to your baby, costs of living whilst travelling to hospital each day and if your baby is severely premature, and the need to take longer maternity leave from work.'*

> *'Talk to people about your experiences. Do not feel afraid to keep asking questions. Remember it is your baby(ies) and you are entitled to have a say in how your baby is looked after. Look after yourselves as visiting SCBU and coping with other dependents at home is stressful and tiring. You do not have to be super parents!'*

The emotional impact and need for support was mentioned by many respondents and their experiences varied:

> *'I think there should be support groups set up in hospitals so that parents can confide in someone about their feelings and worries. Seeing your baby there helpless and you can't really help is a frightening event for any family to go through.'*

*'My baby's early arrival was a complete shock and a very unnerving experience, it was made easier to cope with from the support offered by all the staff at the hospital and also by the excellent support we received following discharge and the continued support we receive as outpatients.'*

*'The experience was relatively well managed by the unit, but there was no emotional or psychological support. I just wish someone had told me it was ok to feel so completely overwhelmed and bewildered by the experience.'*

*'It is a rollercoaster of emotions, and unfortunately it is inevitable. My advice would be to take each day as it comes and enjoy every minute you get with your baby.'*

Higher proportions of parents of sicker and smaller babies responded to the survey than is typical of the general neonatal unit population. Nevertheless this is a group for whom the processes associated with admission to neonatal care, transfers and care itself, may have the biggest impact.

*'Although we were very happy with the care our baby received, having a baby transferred so far away meant that there were no support networks of friends and family on hand. Also, it was three days before I saw my baby after the birth which was very difficult as I was too ill to travel. Then when my baby was transferred back to our local hospital I was not allowed to travel with him and had to get the train back, despite having just been discharged and less than one week after major surgery.*

*This was our 1st child and he was transferred as soon as he was born. It felt like he belonged to the NHS and not us. He was transferred 200 miles away from where we live. We were victims of circumstance as had he been in our local hospital he would have been visited every day'*

In summary, the responses that the study parents provided show how profound the impact was of having a baby admitted and cared for in a neonatal unit for some of them, both at the time and subsequently. Those whose babies were transferred describe the practical and psychological issues very well. While many were uncertain about the role of neonatal networks in the care of their infant, some were clearly aware of the capacity issues in their local and other units that had necessitated their own transfer or that of their baby. They appreciated the benefits of specialist care while experiencing the effects of distance and separation from their families. Parents more generally identified their needs while their baby was in hospital, particularly for information and support and many who participated in the study also emphasised the need for further emotional support, formal and informal, after their baby had been discharged home.

# Section 8: Conclusion

The focus for the 2006 NPEU research project on neonatal care has been on the impact of networks and current level of network functioning, capacity and staffing, and parents' experience of transfer and admission to neonatal care. Data were collected using surveys and interviews. The sources include units and unit managers, network managers, clinical leads for networks and clinical leads within units. The aim has been to utilise the different perspectives to document the present situation in neonatal care and to make comparisons with data collected previously.

## 8.1 Summary of key points

Networks

- Reconfiguration of neonatal services is ongoing
- There is evidence of some streamlining of care and remodelling of unit capacity
- The extent to which functioning managed clinical networks have become established in neonatal care is variable
- The financial basis of network functioning is of concern to units, clinicians, network managers and leads, especially in the context of payment by results
- Shared meetings, staff training and the development of shared protocols are the most commonly reported aspects of successful network functioning
- Transport services have been recognised as a key aspect in network and supra-network functioning

Capacity

- UK neonatal admission rates continue to rise
- Some small units have closed and further closures are planned
- Almost all study units (95%, n=158) commonly exceed their capacity
- Level 1 (Type 1) units are still admitting babies requiring intensive care
- 7% of all ELBW infants were admitted to Level 1 (Type 1) units
- Three-quarters of units had been closed to admissions at some time in the six months prior to the survey

Staffing

- The most frequently reported capacity problem is inadequate nurse staffing
- Although nurse staffing figures have increased since 2005, the nurse workforce in WTE is understaffed by a third
- Only 4% of neonatal units meet the BAPM standards put forward for nurse staffing

### Transport and transfers

- Capacity in the hospital in which the baby was born and the need for specialist services are the main reasons for transfer (excluding back transfers)
- Dedicated transport services are not universally available and supra-network services are operating or being planned in some areas
- The need for accurate data collection on transfers, including 'in utero' transfers is critical for planning and auditing the service

### The parents' perspective

- Parents need to be considered and to be fully informed about the transport process
- Relatively few parents are aware of neonatal networks and of possible impact of network organisation on the transfer of their baby
- Parents value enormously the care that is provided for their babies, however the specific support, information and practical needs of parents whose babies are moved between units should be addressed

The findings of the study, alongside the continued need for more neonatal cots and specialist staff, reflect a need for a more co-ordinated approach to network management and operation, as well as a drive to address the nurse staffing issues in neonatal care.

The present study, based on survey and interview data and carried out at one point in time, was limited in scope and capacity. Future research should involve the utilisation of audit data (such as those collected as part of the SEND project[1], when it is available) for network based studies and larger scale projects. It should also focus on the experience and views of a more representative group of parents, coming from the full range of social and cultural groups whose babies are admitted for neonatal care.

[1] South East England Neonatal Database, http://www.neonatal.org.uk/Healthcare+Professionals/SEND

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