

○ Parents' experiences of neonatal care

A REPORT ON THE FINDINGS FROM A NATIONAL SURVEY

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Picker Institute Europe
November 2011

Picker Institute Europe

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- build and use evidence to champion the best possible patient-centred care
- work with patients, professionals and policy makers to strive continuously for the highest standards of patient experience.

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Published by and available from:

Picker Institute Europe

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Registered charity no 1081688

Company limited by registered guarantee no 3908160

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Acknowledgments

We are very grateful to the parents who participated in the survey, and for those families that helped in the development of the questionnaire by taking part in focus group discussions or cognitive interviews.

Thanks also to the neonatal network managers and lead nurses who worked with their units to ensure the success of the survey. NHS trust staff should be thanked for their work in checking sample lists and, in some cases, for mailing out questionnaires.

Staff at Clevermed Ltd should be acknowledged for all their help and hard work in extracting the sample lists from BadgerNet for many of the neonatal units.

The survey was championed by Bliss, the special care baby charity, and additional funding was provided by the neonatal networks participating in the survey and the Department of Health.

Executive summary

Introduction

The first national survey of parents' experiences of neonatal care was carried out in 2010-11 with 125 neonatal units, including special care baby units, local neonatal units and neonatal intensive care units (see Appendix 2 for a list of participating units). The survey was carried out by 19 neonatal networks and was championed by Bliss, the special care baby charity, and also supported by the Department of Health.

Picker Institute Europe developed and co-ordinated the survey in conjunction with Bliss and neonatal network representatives. The survey was carried out in three 'waves' between summer 2010 and autumn 2011. Almost 20,000 parents were sent a postal questionnaire following their baby's discharge from hospital asking about their experiences of neonatal care. Over 9,000 parents took part in the survey. After taking into account undelivered questionnaires and those parents that were ineligible for inclusion, this is a response rate of 50%.

Key findings

Admission to neonatal care

Where admission of a baby to a neonatal unit was predicted, 41% of parents were given the chance to visit the neonatal unit and 36% said a member of staff definitely came to talk to them about what to expect after the birth.

Most parents (85%) were able to touch their baby before he/she was admitted to the unit, although only 46% were given a photograph of their baby. One in five parents (22%) said that a member of staff did not talk to them about their baby's condition and treatment after the birth.

Following the birth, more than half of the mothers (59%) were cared for on the same ward or area as those mothers who had their baby with them; 32% said they were bothered by this. The majority of respondents – 81% – said that their partner or family member was not allowed to stay with them overnight after the birth of their baby.

On admission to the unit, 74% of parents said infection control practices were explained to them but 43% said they were not given enough information about the neonatal unit (such as rules, procedures and facilities for parents) and 46% were not clearly told about the purpose of the machines, monitors and alarms used in the unit.

Staff on the neonatal unit

Most parents (85%) said that staff referred to their baby by his/her first name, although only 56% reported that when they visited the unit all staff introduced themselves. A high percentage of respondents (86%) said they were told which nurse was responsible for their baby's care each day they were in the unit.

Parents were largely positive about the neonatal staff and their communication with them:

- 76% were always able to talk to staff on the unit about their worries or concerns
- 73% said nurses were always sensitive to their emotions and feelings
- 79% said that staff always kept them up to date with their baby's condition and progress and 78% were always told about any changes in their baby's condition or care
- 79% said staff always explained the purpose of any tests their baby had and, if their baby required surgery, 77% said staff always explained the operation and its outcome in a way they could understand
- 86% said they always had confidence and trust in the staff caring for their baby

The survey highlighted, however, that only 40% of parents said they definitely got enough written information to help them understand their baby's condition and treatment; 27% did not get any written information. Other areas of the survey where parents reported less positive experiences include:

- 29% said that important information about their baby was not always passed on from one member of staff to another
- 44% reported that staff 'sometimes' or 'often' gave them conflicting information

Parental involvement

Parents were largely positive about their involvement in their baby's care:

- 81% were definitely involved as much as they wanted to be in the day-to-day care of their baby, such as nappy changing and feeding
- 77% were definitely encouraged to touch, hold and comfort their baby

However, only 50% of parents said they definitely had as much 'kangaroo care' (skin to skin contact) with their baby as they wanted. Parents' were also less positive about staff involving them in decision-making; only 55% said that staff always included them in discussions about their baby's care and 37% were not always allowed to be present during a ward round when their baby was being discussed.

Around three in four parents responded positively with regard to the support provided to help them feed their baby, whether through expressing breast milk, breast feeding or feeding their baby formula milk

Support for parents

Whilst in general parents were positive about the information and explanations given to them by staff with regard to their baby's condition and treatment, the survey showed that relatively large proportions of respondents said they did not receive information about parent support groups (34%) or any help they could get with travelling expenses, parking costs or food vouchers (53%).

Although most parents (56%) said they did not need any emotional support or counselling, 25% said they were not offered this support but would have liked it.

Transfers to another unit

Of those parents responding to the survey, 13% said their baby was transferred to a neonatal unit at a different hospital. A third of these parents (33%) said that they were cared for in a different hospital to their baby, highlighting one area where parents' experiences could have been better. The survey also showed that:

- 41% of parents were not given enough warning that their baby was being transferred
- 38% were not given enough information about the hospital/unit where their baby was being transferred to
- 31% felt that staff in the new unit were not fully aware of the care their baby had previously received

Discharge from the unit

Most parents (80%) were offered accommodation overnight at the hospital before their baby came home and 75% said they definitely felt prepared for their baby's discharge from neonatal care.

Of those parents whose baby required special equipment when they were discharged home, 78% were definitely given enough information and guidance on using the equipment at home.

The survey highlighted that parents were less positive about the information they were given on what to expect in terms of their baby's progress and recovery; 32% said they were only given enough information 'to some extent' and 15% were not given any information at all.

Care and support at home

Parents were least positive about the care and support they received once their baby had been discharged from the neonatal unit. Almost one in ten parents (9%) said they would have liked some contact with neonatal staff following their baby's discharge but did not have any. Around a quarter of parents (24%) said that their baby had a follow-up appointment at hospital but only 19% said that staff contacted them by telephone and 15% were visited by staff at home.

A relatively high proportion of parents (42%) reported that they did not get enough overall support – or only got enough support 'to some extent' – from health professionals after their baby arrived home. Of those parents who saw a health visitor, only 39% said that they definitely had enough information about the development of babies who had received neonatal care.

Recommendations

1. Neonatal networks and individual neonatal units should use the results of the survey to prioritise areas for improving their parents' experiences of neonatal care. Units can explore those areas where other units have performed better to help understand how improvements can be made and what initiatives could be introduced to improve parents' experiences.
2. Results from the survey can be used to monitor performance at national, network and unit levels against relevant quality standards for neonatal care outlined in the Department of Health's Toolkit for High-Quality Neonatal Service and the NICE Quality Standard for Specialist Neonatal Care.
3. Neonatal units should share the feedback about their services widely with key stakeholders, both within and outside their organisation. Everyone who plays a role in delivering or receiving neonatal services should ideally be aware of and make use of this parent feedback. Commitment from front-line staff is key to implementing changes on the ground, while senior managers can help ensure quality improvement remains a priority for the organisation.
4. To maintain and improve high quality care for babies and their families, a national survey of parents' experiences of neonatal care should be conducted by all units annually, using a standardised methodology and tool. This will allow parents' experiences across units to be compared and performance benchmarked against local and national standards over time. Changes in performance can only be identified if surveys are repeated and, repeated surveys will allow units and networks to measure the impact of quality improvement initiatives from the parents' perspective.
5. Neonatal networks and/or units could use the same questionnaire tool and method to carry out additional surveys between national surveys to continuously monitor performance and measure the impact of any quality improvement initiatives introduced to their neonatal service.
6. To increase the response rate to future national surveys by:
 - Ensuring greater publicity of the survey internally and externally (e.g. posters in units advertising the survey, flyers in discharge packs given to parents, presenting survey results within the unit, press releases, and so on).
 - Revisions to the questionnaire tool to reduce the length of the questionnaire and remove questions shown to be less important to parents and/or of less use for units.
 - Checking there is no overlap with units conducting local surveys at the same time as a national survey.
 - Confirming all parents in the survey sample are eligible by increased checking of sample lists by NHS staff (e.g. to ensure that all babies spent at least 24 hours in the neonatal unit).

Introduction

Background

Neonatal units specialise in the care of babies born early, with low weight, or with a medical condition that requires specialised treatment. The level of neonatal care a baby receives will vary from minimal intervention for a few minutes or hours through to considerable support over many weeks, months or even years. The demand for specialist neonatal care has increased by 9% in the last three years (2006/07–2008/09).²

In 2001, the Department of Health recommended that neonatal services be organised into managed clinical networks, with hospitals working as teams to ensure that babies were cared for in appropriate settings.² Neonatal services are based upon Strategic Health Authority populations and organised as 23 managed clinical networks across England, although several are managed together in consortia relating to specialist commissioning groups.² Each network has, or is developing, its own care pathways, guidelines and clinical audit programmes. Each unit within a network should also have access to 24-hour transfer services to ensure that babies receive care in appropriate settings timed to maximise clinical outcomes.²

As outlined in section 3.8 of the *Toolkit for high-quality neonatal services*², neonatal care takes place in three types of unit:

- **Special care units (SCUs)** provide special care for their own local population. Depending on arrangements within their neonatal network, they may also provide some high dependency services. In addition, SCUs provide a stabilisation facility for babies who need to be transferred to a neonatal intensive care unit (NICU) for intensive or high dependency care, and they also receive transfers from other network units for continuing special care.
- **Local neonatal units (LNUs)** provide neonatal care for their own catchment population, except for the sickest babies. They provide all categories of neonatal care, but they transfer babies who require complex or longer-term intensive care to a NICU, as they are not staffed to provide longer-term intensive care. The majority of babies born at over 27 weeks of gestation will usually receive their full care, including short periods of intensive care, within their LNU. Some networks have agreed variations on this policy, due to local requirements. Some LNUs provide high dependency care and short periods of intensive care for their network population. LNUs may receive transfers from other neonatal services in the network, if these fall within their agreed work pattern.
- **Neonatal intensive care units (NICUs)** are sited alongside specialist obstetric and fetal-maternal medicine services, and provide the whole range of medical neonatal care for their local population, along with additional care for babies and their families referred from the neonatal network. Many NICUs in England are co-located with

neonatal surgery services and other specialised services. Medical staff in a NICU should have no clinical responsibilities outside the neonatal and maternity services.

Why the survey was carried out

Assessing parents' experiences of neonatal services is crucial for an understanding of how the quality of care can be improved. Principle 4 of the Bliss Baby Charter Standard states that "developing a culture of continuous improvement, that involves and is informed by parents, maintains high quality care for babies and their families and encourages units to continually raise the bar in provision of family-centred care".⁶

Previous research has shown parents' experiences of neonatal care, and the extent to which services are 'family-centred', can vary enormously between units.⁴ Whilst a number of neonatal units and/or networks were already carrying out their own parent satisfaction surveys, participating in a national survey using a standardised tool and methodology was recognised to be valuable for benchmarking unit performance against national findings as well as with similar services in terms of the type of unit or location. Each neonatal unit has been provided with three separate reports which benchmark their performance against 1) national findings, 2) other units of the same 'type' (i.e. all Special Care Baby Units, all Local Neonatal Units or all Neonatal Intensive Care Units) and 3) other units within the same neonatal network.

The importance of ensuring that neonatal care is family-centred and parent-focused has been increasingly recognised in recent years. The NHS Neonatal Taskforce, which was established in response to the National Audit Office report on the reorganisation of neonatal care¹, agreed a set of measures to support the delivery of high quality neonatal services as outlined in the 'Toolkit for High-Quality Neonatal Service.'² The third principle in the toolkit, 'care of the baby and family experience', sets out a number of markers of good practice which puts the physical, psychological and social needs of both the baby and their family at the centre of all care provided. The parents' neonatal survey is an important source of data for measuring performance against this principle.

In addition, the National Institute for Health and Clinical Excellence (NICE) published a quality standard in 2010 to address the care provided for babies in need of specialist neonatal service³. There are a number of quality measures accompanying the standard which aim to improve the structure, process and health outcomes of neonatal care. This national parents' neonatal survey was recognised by NICE as a method for collecting evidence for assessing parent involvement in care and decision-making (i.e. quality statement 5).

Throughout the report we highlight results that are related to key standards. A full summary of how survey domains relate to various standards is included in appendix 4, table 1.

How the survey was carried out

Each neonatal unit participating in the survey was required to send the Picker Institute a sample of parents whose babies were discharged home over a specified three month

sampling period.* Parents were ineligible for inclusion if their baby had stayed in a neonatal unit for less than 24 hours, if the baby's mother was aged under 16 years at the time the sample was drawn or if the baby had been taken into care.

For the majority of units that use the BadgerNet platform for recording and managing their neonatal data, Clevermed Ltd extracted the sample list for the units according to inclusion/exclusion criteria as specified by the Picker Institute. The sample list could be accessed by a member of the NHS trust staff who had the correct permissions to view patient identifiable data. Other units, not using BadgerNet, compiled the samples from trust records by following detailed guidance instructions provided by the Picker Institute. All units were required to check with the NHS Demographic Batch Service that none of the mothers or babies had died following discharge to ensure that questionnaires were not mailed to recently bereaved families.

The survey was conducted in three 'waves' in order to obtain a sufficiently sized sample to allow the results to be presented at unit-level:

- Wave 1: sample compiled in July 2010 (babies discharged April-June)
- Wave 2: sample compiled in October 2010 (babies discharged July-September)
- Wave 3: sample compiled in January 2011 (babies discharged October-December)

Parents were sent a questionnaire to complete at home and up to two reminders were sent to non-responders (the second reminder included another copy of the questionnaire). If parents decided to take part in the survey, they could return their completed questionnaire to the Picker Institute in a freepost return envelope. Parents could also complete the questionnaire over the phone with the help of a researcher and with the additional help of an interpreter if required.

Development of the questionnaire

The questionnaire used in the survey was developed by Picker Institute Europe in consultation with Bliss and the neonatal network representatives. Previous questionnaires examining parent satisfaction with and experiences of neonatal care were initially reviewed, as were recent research studies (such as the POPPY project⁴) and policy and quality standards on neonatal care.

Focus groups were carried out with parents who had recently experienced neonatal care to establish the issues that were of most importance to them. Following the literature review and focus groups, a draft questionnaire was developed and a number of cognitive interviews were conducted with parents to test the relevance and validity of the questionnaire. Many revisions were made to the questionnaire during this testing phase, and further amendments were made to the tool following consultation with Bliss and the network representatives.

Please see Appendix 1 for further information on the development of the questionnaire.

* The questionnaire was sent to a random sample of 60 parents of babies who were discharged home per unit over the three month sampling period (or all parents if fewer than 60 babies were discharged in the sampling period)

Summary of key findings

This section provides a broad overview of the main survey findings, focusing on those areas where, at a national level, parents reported their most positive and least positive experiences of neonatal care. Those questions showing the greatest variation across neonatal units in parents' experiences are also highlighted.

The survey results are discussed in further detail in the rest of the report, examining the parents' journey from their baby's admission to neonatal care to their discharge home. The results for each question included in the survey are shown in Appendix 4, and the results are broken down for particular groups of respondents (such as by parents' age) in Appendix 6.

Positive parent experience

Parents reported positive experiences of neonatal care in the following areas:

- 99% said there were facilities for the storage of breast milk on the unit
- 95% reported that their partner/companion was able to see their baby as soon as they wanted following their baby's admission to the neonatal unit
- 93% said staff always washed or cleaned their hands before touching their baby
- 89% were able to visit their baby as much as they wanted to and 92% were able to contact the unit by telephone whenever they needed
- 86% reported always having confidence and trust in the staff caring for their baby
- 86% said that staff always treated them with respect and dignity
- 85% said staff referred to their baby by his/her first name
- 84% of parents said staff clearly explained why their baby was being transferred to a different hospital
- 80% were offered accommodation overnight at the hospital before their baby was discharged
- 79% said a member of staff always explained the purpose of any tests their baby had in a way they could understand
- 73% said nurses were always sensitive to their emotions and feelings

Key areas for improvement

Parents reported least positive experiences in the following areas:

- 81% said that after they gave birth their partner or family member was not allowed to stay with them overnight
- 65% said they were not able to speak to a doctor about their baby as much as they wanted
- 61% said the health visitor who visited them at home following discharge did not have enough information about the development of babies who had received neonatal care
- 56% were not always offered overnight accommodation if they wanted to be close to their baby
- Information provision:
 - 53% did not get any information about any help they could get with travelling expenses, parking costs or food vouchers
 - 34% did not get any information about parent support groups
 - 34% said they were not given enough written information to help them understand their baby's condition and treatment and a further 27% said they did not get any written information at all
- Where admission to the neonatal unit was predicted, 43% said a member of staff from the neonatal unit did not talk to them about what to expect after the birth
- 32% said there was nowhere for their other children to play when visiting the unit and a further 10% said children were not allowed to visit
- 32% were bothered about being cared for in same ward as mothers who had their babies with them
- 25% were not offered emotional support or counselling services but would have liked it

Variations across units in parents' experiences

Table 1 shows those questions in the survey which showed the greatest variation in parents' reported experiences across units.

The individual responses to questions in the survey were converted into scores on a scale of 0 to 100 to indicate the extent to which the parents' experience could be improved; a score of 0 is given to any response option(s) that suggest considerable scope for improvement, whereas a score of 100 is given to any response option(s) that shows the best possible experience. The higher the score for each question, the better the unit is performing. The overall unit score for each question is calculated as an average of the

individual scores. Those questions where the range in the overall unit scores was greater than 50 are presented in Table 1. This shows where there is the greatest room for improvement for those units scoring low at these questions.

Table 1: Questions showing a large variation in parents' experiences across units

Survey question	Minimum unit score	Maximum unit score	Range across units
A2 Before your baby was born, were you given the chance to visit the neonatal unit?	31	85	54
A3 Before your baby was born, did a member of staff from the neonatal unit talk to you about what to expect after the birth?	17	76	59
B3 Were you given a photograph of your baby?	11	100	89
B4 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?	27	88	61
B9 After you gave birth, was a partner or family member allowed to stay with you overnight?	2	80	78
E7 When a ward round was taking place, were you allowed to be present when your baby was being discussed?	20	96	76
E8 Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	34	92	57
F5 If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?	15	89	74
F8 If you had your other children with you when visiting the unit, was there somewhere they could play?	0	62	62
G7 Were you offered emotional support or counselling services?	11	71	60
G8 Were you given information about any help you	5	74	69

could get with travelling expenses, parking costs or food vouchers?			
G9 Did staff give you any information about parent support groups, such as Bliss or other local groups?	23	80	57
H9 After your baby arrived home, did you have contact with neonatal staff?	13	96	84

Question domains

To help understand which area(s) of neonatal care parents reported the most positive experiences and those where there is most room for improvement, scored questions have been grouped and aggregated to form a single composite score for 7 domains. A factor analysis was undertaken to determine these domains which is described in Appendix 4. The questions included in each domain are presented in Appendix 4 mapped to relevant quality standards for neonatal care (Appendix 4, Table 1).

The domain with the highest overall mean score was 'trust and confidence in staff' indicating that parents were most positive about the communication and support provided by staff and their relationship with staff caring for their baby (Table 2). In contrast the areas of care where parents reported the least positive experiences overall were 'co-ordinated discharge planning' and 'interaction with doctors' (Table 2).

Table 2: Overall question domain scores by type of unit

Domain	National (125 units)			Special Care Baby Units (38 units)			Local Neonatal Units (53 units)			Neonatal Intensive Care Units (34 units)		
	Mean	Min	Max	Mean	Min	Max	Mean	Min	Max	Mean	Min	Max
Trust and confidence in staff	85	73	93	85	76	91	85	74	93	85	73	91
Knowledge and information sharing	78	64	94	78	64	94	78	67	86	77	64	91
Active Care	80	64	91	80	64	91	80	68	89	80	71	86
Empowered decision making	75	45	93	78	54	93	74	52	87	73	45	89
Privacy for breastfeeding	84	61	95	84	61	95	84	71	94	85	63	95
Co-ordinated discharge planning	67	49	83	67	56	83	67	49	78	67	56	75
Interaction with doctors	69	55	83	68	55	80	69	57	79	70	60	83

There were no statistically significant differences in the mean domain scores by the type of unit that a baby was discharged from. The mean score for Special Care Baby Units (SCBUs) was higher for the 'empowered decision making' domain (78) compared with Local Neonatal Units (74) and Neonatal Intensive Care Units (73). This suggests that parents whose baby was discharged from a SCBU were more positive about their experiences of being involved in their baby's care when compared with parents whose babies were discharged from the other types of unit. In contrast, the mean score for the 'interaction with doctors' domain was higher for units providing more complex or longer-term care: the mean domain score for SCBUs was 68 compared with 69 for LNUs and 70 for NICUs suggesting that parents are more positive about the sensitivity shown by doctors and were able to speak with a doctor as much as they wanted if their baby was discharged from a unit providing higher level care. Although these differences are not statistically significant they nevertheless highlight the main areas where parents reported experiences differ depending on unit type.

The data was also analysed to test for differences in domain scores by key groups of respondents. Few significant differences were found and consequently these tests are not reported.

Variations in the experiences of parents

In general, parents' reported experiences of neonatal care were more positive if they were older and their baby was born at an earlier gestational age (and/or if their baby was of lower birth weight and/or spent longer in a neonatal unit). The data have therefore been standardised by the age of respondents and by the gestational age of their baby at birth. This standardisation was particularly important for the unit-level reports to ensure that no unit appeared better or worse than another because of its respondent profile.

A breakdown of the results by key groups of respondents is presented in Appendix 6.

Admission to neonatal care

Pre-natal experience

Preparing parents for their baby's time in the neonatal unit is important as the experience can be shocking and stressful. Previous research has shown parents appreciate having a tour of the neonatal unit and being informed about what to expect after the birth.^{4,5}

Toolkit for high-quality neonatal services

3.1 Where admission to a neonatal unit is predicted, a pre-natal opportunity to visit the neonatal unit and meet key personnel is offered to the family

Around one third of parents (32%) responding to the survey knew that their baby might need care in a neonatal unit. Of these, 41% said they were given the chance to visit the unit before the birth but almost a quarter (21%) said they would have liked to have visited but were not given the chance. Of those parents who expected their baby would spend time in a neonatal unit, only one third (36%) said that a member of staff from the unit definitely talked to them about what to expect after the birth.

The survey showed that a significantly higher proportion of parents whose babies were born at an earlier gestational age, had a lower birth weight and spent a longer length of time in the unit were given the chance to visit the neonatal unit and have spoken to a member of staff from the unit about what to expect after the birth (Appendix 6). This finding is perhaps unsurprising given that these factors are perhaps all indicative of babies that have greater needs and require more intensive care.

After the birth

In the focus groups carried out during the development of this survey, parents said that touching or seeing their baby (or receiving a photograph) before s/he went to the neonatal unit was important; and some hospital staff made sure that this happened.

The majority of parents responding to the survey (85%) said they were able to touch their baby before they were admitted to the neonatal unit[†] although less than half of respondents (46%) said they were given a photograph of their baby. The survey showed a large variation across units with regard to the percentage of parents reporting that they had been given a photograph of their baby, ranging from just 2% of respondents at one unit to 90% at another.

In the first few hours after the birth, it is known that parents appreciate being contacted by a member of staff from the neonatal unit to inform them about their baby's progress.⁴ One in five parents who responded to the survey (22%) said that a member of staff did not come to talk to them about their baby's condition and treatment after the birth. Of those parents aged 36 and over, 80% said a member of staff came to talk to them compared with just 75% of parents aged 16-27 years (Appendix 6)

[†] This figure excludes parents that were unable to touch their baby due to medical reasons.

Mothers of babies admitted to a neonatal unit can find it difficult to be cared for on the general postnatal ward with mothers and babies. Research has shown that mothers who are separated from their babies want to be treated with sensitivity at this time but that this need is not always met.⁵ The survey showed that 59% of mothers were cared for on the same ward as those mothers who had their babies with them; over half of these (32%) said they were bothered by this. The results suggest that mothers of babies born with greater medical need (i.e. babies born at any earlier gestation, of lower birth weight, requiring a longer length of stay, and admitted to a neonatal intensive care unit) were more likely to report being cared for in a separate room or area following the birth (Appendix 6). For instance, of those babies born weighing less than 1000 grams, 52% of their mothers were cared for in a separate room or area compared with just 38% of mothers whose babies were born weighing more than 2500 grams. Whilst it is perhaps understandable that hospitals may prioritise separate rooms/areas for those mothers of babies requiring more intensive care and treatment, there is nevertheless a large variation across units in the proportion of mothers who said they were cared for in a separate room (11%-80%).

Another area where the results vary widely across units is with regard to whether or not partners/family members were allowed to stay overnight after the birth. Whilst overall 81% of respondents said that a partner or family member was not allowed to stay with them overnight after the birth, this ranged from just 20% of respondents at one unit to almost all respondents (98%) at another, highlighting one area where some units could make considerable improvement.

On admission to the unit

Providing parents with information about the neonatal unit, such as the facilities available to them and the purpose of the technology used to stabilise and monitor the babies, is important to help parents familiarise themselves with the unit at a traumatic time.^{2,4} The alarms and monitors used in neonatal units were a major concern for parents in all the focus groups that were conducted as part of the development of the survey.

Toolkit for high-quality neonatal services

3.2 All parents are introduced to facilities, routines, staff and equipment on admission to a neonatal unit

Almost half of parents (43%) said that they were not given enough information, or only given information 'to some extent' about the neonatal unit. A similar proportion of parents (46%) reported that the purpose of the machines, monitors and alarms used in the unit was not clearly explained to them. In contrast, almost three quarters of parents (74%) said that infection control practices were definitely explained to them.

There were no statistically significant differences between the different 'types' of units with regard to parents experiences of the information provided about the unit and explanations on infection control practices. However, a significantly higher proportion of parents whose baby stayed in a special care baby unit reported that the purpose of the machines and monitors was explained to them (56%) compared with local neonatal units (54%) and neonatal intensive care units (51%).

Staff on the neonatal unit

Relationship with staff

One criterion for achieving standard 5.1 ('Introducing parents to the unit') of the Bliss Baby Charter is that unit staff should introduce themselves to parents and explain their role in relation to their baby's care and the running of the unit. Just over half of parents responding to the survey (56%) said that all of the staff introduced themselves when they visited the unit, although this ranged between 31% and 83% of respondents across units. A higher proportion of parents overall (85%) said that staff always, or nearly always, referred to their baby by his/her first name, but again fairly large variations were evident across units: at the highest scoring unit for this question, 99% of parents said that staff always/nearly always referred to their baby by his/her first name, compared with just 50% of parents at the lowest scoring unit for this question.

The focus groups undertaken with parents during the development of the survey showed that the personal qualities of staff were of primary importance to parents during their journey through neonatal care; parents said that the 'personal touch' of considerate and sensitive staff made all the difference. Seventy six percent of parents responding to the survey said that they were always (or nearly always) able to talk to staff on the neonatal unit about their worries and concerns. However of those parents in the youngest age group (aged 16-27), a significantly lower percentage of parents reported that they were always able to talk to staff about their worries or concerns (69%) when compared with those parents aged 36 and over (80%).

Parents have reported that it is important to have a good rapport with nurses caring for their baby on the unit and to be offered support by them.⁴ Almost three quarters of parents responding to the survey (73%) said that nurses were always, or nearly always, sensitive to their emotions and feelings. This compares with just 63% of parents who reported that doctors were always/nearly always sensitive to their emotions and feelings. Interestingly, whilst there were no significant differences in the proportions of parents reporting that nurses were sensitive to their emotions by the 'type' of unit their baby was discharged from, there were significant differences in parents' experiences of doctors being sensitive to their emotions and feelings by unit-type (Appendix 6). Of those parents whose baby was discharged from a neonatal intensive care unit, 67% said that doctors were always, or nearly always, sensitive to their emotions or feelings compared with just 62% of parents whose baby was discharged from a local neonatal unit and 61% of parents whose baby was discharged from a special care baby unit.

Only 36% of parents said they were always, or nearly always, able to speak to a doctor about their baby as much as they wanted (ranging from 19% to 65% across units). Almost half of parents (46%) said they were only able to speak to a doctor as much as they wanted 'to some extent' whilst 19% said they were not able to speak to a doctor as much as they wanted. As perhaps expected, higher proportions of those parents of babies who appeared to have greater health needs (i.e. babies born at an earlier gestation, babies born lower weight and babies that stayed in the unit longer) said they were always able to speak to a doctor about their baby (Appendix 5). For instance, 38% of parents whose baby stayed in neonatal care for more than one week said they were always able to speak to a doctor compared with 32% of parents whose baby stayed in the unit for less than one

week. Given this finding, it might be expected that parents of those babies discharged from units providing a higher or more intensive level of care would be more likely to report being able to speak to a doctor as much as they wanted. However, the survey showed no significant differences in the proportions of parents who said they were able to speak to a doctor as much as they wanted by the type of unit that their baby was discharged from (Appendix 6).

Information and communication

Toolkit for high-quality neonatal services

3.9 Written information is available (in languages and formats appropriate to the local community) to all users of the service on medical and surgical treatments, to permit early and effective communication with parents covering at least:

- Condition/diagnosis
- Treatment options available
- Likely outcomes/benefits of treatment
- Possible complications/risks
- Possible tests and investigations

The survey showed that parents were largely positive about their experiences of staff communicating information to them:

- 86% said that they were told which nurse was responsible for their baby's care each day they were in the unit (64%-100% across units)
- 79% said that staff always, or nearly always, kept them up to date with their baby's condition and progress (57%-95% across units)
- 79% said a member of staff always, or nearly always, explained the purpose of any tests their baby had in a way they could understand (61%-92% across units)
- 77% said a member of staff always, or nearly always, explained the operation and its outcome in a way they could understand if their baby had surgery (numbers at unit-level too low to report range)
- 78% said that staff always, or nearly always, told them about any changes in their baby's condition or care (59%-93% across units)

Parents were less positive, however, about the amount of written information they were given to help them understand their baby's condition and treatment. Only 40% of respondents said that they 'definitely' got enough written information and over a quarter (27%) reported that they did not get any written information at all to help them understand their baby's condition. In the lowest scoring unit for this question, 42% of parents said they did not get any written information compared with just 16% of parents at the highest performing unit which shows one area where some units could make a significant improvement.

Although there were no significant differences in the experiences of parents receiving written information by the 'type' of unit their baby was discharged from (i.e. SCBU, LNU or NICU), higher proportions of parents reported that they definitely got enough written information if their baby had greater health needs (i.e. babies born at an earlier

gestational age, and/or babies with a lower birth weight and/or babies that stayed in the unit for longer). For example, of those parents of babies who stayed in a neonatal unit for longer than one week, 47% reported that they were 'definitely' given enough information to help them understand their baby's condition and treatment compared with just 31% of parents whose baby stayed in the unit for less than one week (Appendix X)

Of those parents who needed help understanding written or spoken English, 78% said that information was provided in a language they could understand.

One of the criteria outlined in the Bliss Baby Charter for achieving principle 2 on decision-making, is that parents have open access to their baby's records.⁶ One in five parents (20%) said they did not read their baby's medical notes but would have liked to and 27% reported that they did not know about or see the medical notes. The proportions of parents reporting that they read their baby's medical notes varied across units from 23% to 80%.

Confidence in staff

Participants in all four focus groups, conducted during the development of the questionnaire, described the clinical care their baby received as excellent overall despite differences between neonatal facilities in different units. They praised the clinical expertise of staff, 'state of the art' equipment, and the attention their babies got when things went wrong. The survey supports this finding as 86% of parents said that they always, or nearly always, had confidence and trust in the staff caring for their baby.

Almost all parents (93%) reported that, as far as they knew, staff always or nearly always washed or cleaned their hands before touching their baby. Of those parents who said that staff did not wash or clean their hands before touching their baby, only 33% said they always or nearly always had confidence and trust in staff compared with 90% of parents who said that staff always washed or cleaned their hands before touching their baby (Table 3)

Table 3: Parents overall confidence and trust in staff by whether or not staff washed or cleaned their hands before touching their baby

		Overall, did you have confidence and trust in the staff caring for your baby?			Total
		Yes, always or nearly always	Yes, sometimes	No	
As far as you know, did staff wash or clean their hands before touching your baby?	Yes, always or nearly always	7043 89.7%	724 9.2%	85 1.1%	7852 100.0%
	Yes, to some extent	261 49.2%	217 40.9%	52 9.8%	530 100.0%
	No	25 32.9%	27 35.5%	24 31.6%	76 100.0%
Total		7329 86.7%	968 11.4%	161 1.9%	8458 100.0%

($\chi^2=1148$, $df=4$, $p < 0.001$)

Around a quarter of parents (24%) said that important information about their baby was only 'sometimes' passed on from one member of staff to another and a further 5% said the information was not passed on at all. The proportion of parents who said that important information about their baby was always/nearly always passed on ranged between 46% and 90% across units. As shown in Appendix 6, a significantly higher proportion of parents in the oldest age group said that important information about their baby was passed from one member of staff to another when compared with those parents aged 16-27 years (76% compared with 64% respectively).

Another area of the survey that parents reported a less positive experience was with regard to receiving conflicting information from staff about their baby's condition or care. A quarter of parents (26%) said that staff 'sometimes' gave them conflicting information and 18% said that staff 'often' did. Previous qualitative research has shown that parents find it very distressing to be given conflicting advice about how to care for their baby,⁵ and the importance of parents being given consistent information from staff is recognised in the Bliss Baby Charter Standards.⁶ Of those parents who said that staff 'often' gave them conflicting information, 22% said they did not always have confidence and trust in the staff caring for their baby compared with just 7% of parents who were not given any conflicting information (Table 4). The survey showed considerable variation across units in parents' reported experiences of being given conflicting information: in the poorest performing unit for this question, 46% of parents said that staff often gave them conflicting information compared with just 13% of parents at the highest scoring unit.

Table 4: Parents overall confidence and trust in staff by whether they received conflicting information from staff about their baby's condition or care

		Overall, did you have confidence and trust in the staff caring for your baby?			Total
		Yes, always or nearly always	Yes, sometimes	No	
Did staff give you conflicting information about your baby's condition or care?	Yes, often	1292 78.3%	276 16.7%	82 5.0%	1650 100.0%
	Yes, sometimes	1794 74.3%	538 22.3%	84 3.5%	2416 100.0%
	No, not at all	4769 93.1%	312 6.1%	42 .8%	5123 100.0%
Total		7855 85.5%	1126 12.3%	208 2.3%	9189 100.0%

($X^2=580$, $df=4$, $p < 0.001$)

Parental involvement

Involving parents in decision-making

Principle 2 of the Bliss Charter states that decisions on the baby's best interest should be based on evidence and best practice, and are informed by parents who are encouraged and supported in the decision-making process.⁶ It is reasoned that treating parents as partners in their baby's care provides the balance between baby and family-centred care. Both the Department of Health's toolkit and the NICE quality standards for neonatal care identify the importance of parents being involved in decision-making about the care and treatment of their baby.

NICE Specialist Neonatal Care Quality Standard

5a) Evidence of local arrangements to involve parents in decision-making processes

Toolkit for high-quality neonatal services

3.4 Parents are encouraged and supported to participate in decision-making about the care and treatment of their baby. Written and regularly updated care plans are shared with parents. Clinical care decisions are made by experienced staff in partnership with the parents and discussions held in an appropriate setting.

Just over half of parents (55%) reported that doctors and nurses 'always' included them in discussions about their baby's care and treatment, with the remaining 46 per cent responding that this happened only 'sometimes' or not at all. At the best scoring unit for this question, 75% of parents reported that doctors and nurses always included them in discussions about their baby's care. In contrast, only 35% of parents at the lowest scoring unit said they were always included in such discussions highlighting one area where considerable improvement can be made.

A higher overall proportion of parents (63%) said that they were always, or nearly always, allowed to be present during a ward round when their baby was being discussed. Inviting parents to be present at ward rounds is recognised as one criterion for achieving standard 2.1 of the Baby Charter on involving parents on an equal basis in the decision-making process.⁶ Of those parents who said they were always or nearly always allowed to be present during a ward round when their baby was being discussed, 67% reported that doctors and nurses included them in discussions about their baby's care when compared with only 33% of those parents who were not allowed to be present (Table 5).

Table 5: Parents presence during ward rounds by involvement in discussions about their baby's care and treatment

		Did the doctors and nurses include you in discussions about your baby's care and treatment?			Total
		Yes, always	Yes, sometimes	No	
When a ward round was taking place, were you allowed to be present when your baby was being discussed?	Yes, always or nearly always	3373 67.1%	1481 29.4%	175 3.5%	5029 100.0%
	Yes, to some extent	556 39.1%	718 50.5%	147 10.3%	1421 100.0%
	No, I was not allowed to be there	503 32.9%	611 40.0%	415 27.1%	1529 100.0%
Total		4432 55.5%	2810 35.2%	737 9.2%	7979 100.0%

($X^2=1195$, $df=4$, $p < 0.001$)

Parents' reported experience of whether or not they were allowed to be present during a ward round differs by the 'type' of unit (i.e. level of care provided) from which their baby was discharged. Of those parents whose baby was discharged from a special care baby unit, 70% reported that they were allowed to be present during ward rounds compared with only 61% of parents whose baby was discharged from a local neonatal unit and 58% of parents from a neonatal intensive care unit (Appendix 6).

Involving parents in providing care

NICE Specialist Neonatal Care Quality Standard

5b) Evidence of local audit demonstrating active involvement of parents in providing care for their baby

Toolkit for high-quality neonatal services

3.5 Parents are encouraged and supported to participate in their baby's care at the earliest opportunity, including:

- regular skin-to-skin care;
- providing comforting touch and comfort holding, particularly during painful procedures;
- feeding; and
- day-to-day care, such as nappy changing

The active involvement of parents in caring for their baby while they are in neonatal care is recognised as a key marker for a high-quality neonatal service.^{2,3,6} Enabling parents to help to care for their baby facilitates development of the parental relationship thereby allowing the baby and their family to achieve the best quality of life.⁶ The qualitative work carried out to develop the questionnaire for this survey, showed that parents found doing practical things for their baby like changing nappies, feeding, dressing and bathing were vitally important in bonding, improving confidence and helping them feel like 'proper' parents. They found it helpful if staff recognised their need to be involved and encouraged and supported their efforts.

A relatively high proportion of respondents (81%) to the survey said that they were 'definitely' involved as much as they wanted to be in the day-to-day care of their baby, with 77% reporting that their partner or companion was involved as much as they wanted to be. The survey asked parents if staff arranged their baby's care (such as nappy changing and feeding) to fit in with their usual visiting times, as this may help to support parents to participate in their baby's daily routine.

Just over half of all parents (55%) said that staff always, or nearly always, arranged their baby's care to fit in with their usual visiting times, although a quarter (24%) reported that this only 'sometimes' happened and 21% said staff did not do this. There was a large variation in parents' experiences of staff arranging their baby's care to fit in with their usual visiting times; at the best performing unit for this question (i.e. scored 96 out of 100), 87% of parents said that staff always or nearly always arranged their baby's care to fit in with their usual visiting times, compared with just 17% of parents at the poorest performing unit for this question.

Table 6 shows that of those parents who said that staff arranged their baby's care to fit in with their usual visiting times, 92% said they were 'definitely' involved as much as they wanted in the day to day care of their baby compared with just 61% of parents who

reported that staff did not arrange their baby's care to fit in with their usual visiting times.

Table 6: Parents involvement in the day-to-day care of their baby by their baby's care being arranged to fit in with their usual visiting times

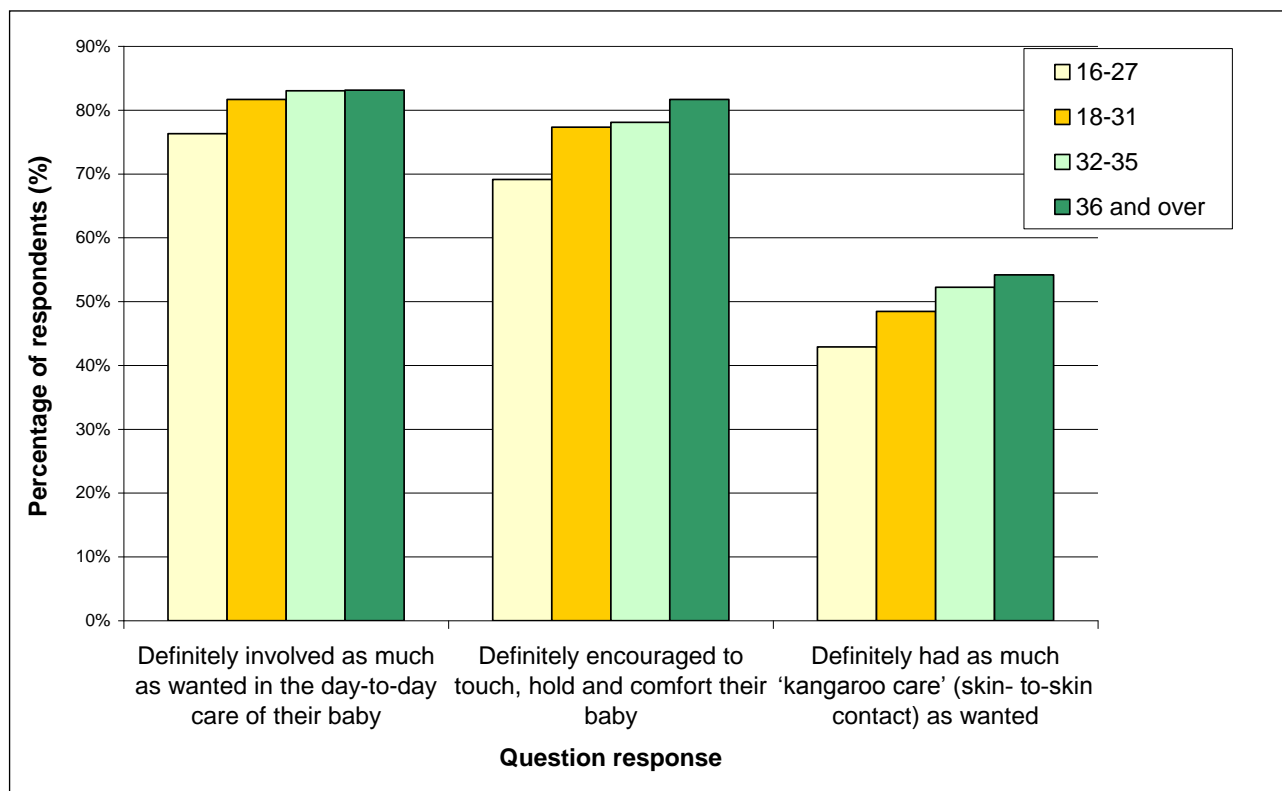
		Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?			Total
		Yes, definitely	Yes, to some extent	No, I was not involved as much as I wanted	
Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	Yes, always or nearly ways	4556 91.8%	329 6.6%	77 1.6%	4962 100.0%
	Yes, sometimes	1566 73.8%	462 21.8%	93 4.4%	2121 100.0%
	No	1132 61.4%	436 23.6%	277 15.0%	1845 100.0%
Total		7254 81.3%	1227 13.7%	447 5.0%	8928 100.0%

$\chi^2=1075$, $df=4$, $p < 0.001$

Three quarters of parents (77%) said they were 'definitely' encouraged to touch, hold and comfort their baby, with just 5% reporting that this was not the case in their experience (ranging between 0% and 26% across units). A much smaller proportion of parents, 50%, said that they definitely had as much 'kangaroo care' (skin-to-skin contact) with their baby as they wanted, ranging between 22% and 79% across units. One in ten parents responding to the survey (11%) said that they did not know about kangaroo care.

The survey showed differences in parents' reported experiences of their involvement in their baby's care by age group (Figure 1). A significantly smaller proportion of the parents in the youngest age group reported being involved as much as they wanted to be in the day-to-day of their baby, being encouraged to hold and comfort their baby and having as much kangaroo care with their baby as they wanted.

Figure 1: Parents' involvement in their baby's care by age group



Support with feeding

The benefits of breast milk for nutritional management are widely recognised; breast milk can help with enteral nutrition, promotes growth and reduces infections and related complications.⁶

NICE Specialist Neonatal Care Quality Standard

6) Mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk

Toolkit for high-quality neonatal services

3.10 Maternity and neonatal services encourage breastfeeding and the expression of milk through the provision of information and dedicated support, including the availability of a comfortable, dedicated and discreet area and the availability of breast pumps and associated equipment

The POPPY research project with parents of neonates has shown that the information and support for expressing breast milk and for breastfeeding could be better so that women have realistic expectations, adequate privacy and practical help.⁴ This survey showed that at a national level a similar proportion of women said that they were definitely given the support they needed to express breast milk (76%), breastfeed their baby (74%) and bottle feed their baby formula milk (74%). A high percentage of women (85%) said they were given the equipment they needed to express breast milk for their baby, such as a breast pump, and almost all parents reported facilities on the unit for the storage of breast milk (99%).

The overall proportions of parents who said they were definitely given enough privacy for expressing milk and for breastfeeding their baby were relatively high (77% and 67% respectively). Although there were no significant differences by the 'type' of unit a baby was discharged from (i.e. SCBU, LNU or NICU) with regard to parents' satisfaction with the amount of privacy provided for expressing milk or breastfeeding, the survey showed variation in parents' experiences across units. The proportion of parents reporting that they were definitely given enough privacy for expressing milk for their baby ranged from just 37% at one unit to 93% at another. A similar range across trusts was evident in the proportion of parents reporting that they were definitely given enough privacy for breastfeeding (29%-90%), highlighting one area where there is scope for some units to make considerable improvement.

Support for parents

Information provision

The POPPY research project highlighted that parents value being able to develop a rapport with other parents on the neonatal unit and appreciate educational and support groups led by a health professional.⁴ One of the markers of a high-quality neonatal service, as outlined in the toolkit, is the provision of information to parents in a number of areas, including national and local support groups.²

Toolkit for high-quality neonatal services

3.8 Written information is available to all users of the service to permit early and effective communication with parents covering at least:

- national and local support groups available
- where to go for further information and support, including sources of financial support and useful websites

3.14 Trusts have policies to provide financial support for families during long-term admission and/or long-distance transfer away from their local unit. Information about this financial support is made available to families

One third of parents who responded to the survey (34%) said that they did not receive any information about parent support groups such as Bliss or other local groups, either from staff directly or from the unit (such as leaflets in a parents' room), ranging between 9% and 66% across units. Perhaps unsurprisingly, higher proportions of parents reported that they received this information if their baby was born at an earlier gestational age and/or was of a lower birth weight and/or stayed in the unit for more than one week (Appendix 6). Similarly, higher percentages of parents whose babies appeared to have more complex and greater needs, said they were given information about help they could get with travelling expenses, parking costs or food vouchers (Appendix 6). For example, of those parents whose baby stayed in a neonatal care unit for more than one week 28% said they were given this information, compared with just 20% of those parents of babies who stayed in the unit for less than a week. Overall, 53% of parents said they were not given information about any help they could get with travelling expenses, parking costs or food vouchers.

Emotional support

Research has shown that many parents appreciate the opportunity to talk to a counsellor whilst their baby is being cared for in a neonatal unit.⁴ Standard 2.3 of the Bliss Baby Charter states that the psychological aspects of care for the whole family should be recognised and included throughout the baby's care pathway and it is one of the markers of good practice outlined in the toolkit for high-quality neonatal services.²

Toolkit for high-quality neonatal services

3.12 Families are able to easily access psychological and social support and parents are given written information about relevant services, such as local and national support groups, counselling, social services and benefits advice

Whilst more than half of parents responding to the survey said they did not need any emotional support or counselling, a quarter (25%) said they were not offered this support but would have liked it. At the national level, only 18% of parents said they were offered emotional support or counselling services and this was as low as 5% of parents at two units. As perhaps expected, significantly higher proportions of parents whose babies appeared to have more complex needs and require specialist neonatal care for longer (i.e. born at an earlier gestational age, had a lower birth weight, had a longer length of stay in the unit and were discharged from a neonatal intensive care unit) said they were offered emotional support or counselling services (Appendix 6). For instance, of those parents whose baby weighed less than 1000 grams at birth, 39% said they were offered emotional support or counselling compared with just 15% of parents whose baby was born weighing more than 2500 grams.

The neonatal unit environment

The toolkit for high-quality neonatal services outlines a number of facilities that should be made available for parents of babies receiving neonatal care, a few of which are outlined below:

Toolkit for high-quality neonatal services

3.11 Dedicated facilities are available for parents and families of babies receiving neonatal care, including overnight accommodation for parents, a play area for siblings of infants receiving care.

The survey has shown that parents of babies born with more complex needs, requiring more intensive and longer periods of time in neonatal care, generally appear to report more positively with regards to receiving information and support from staff (as outlined above). Conversely, of those parents whose baby was born at a later gestational age and/or of a greater birth weight and/or had a shorter length of stay in the unit, higher proportions reported that the hospital offered them accommodation if they wanted to stay overnight to be close to their baby (Appendix 6). Significant differences were also evident by the age group of respondents, with higher proportions of parents in the older age groups reporting that they were offered overnight accommodation (Appendix 6).

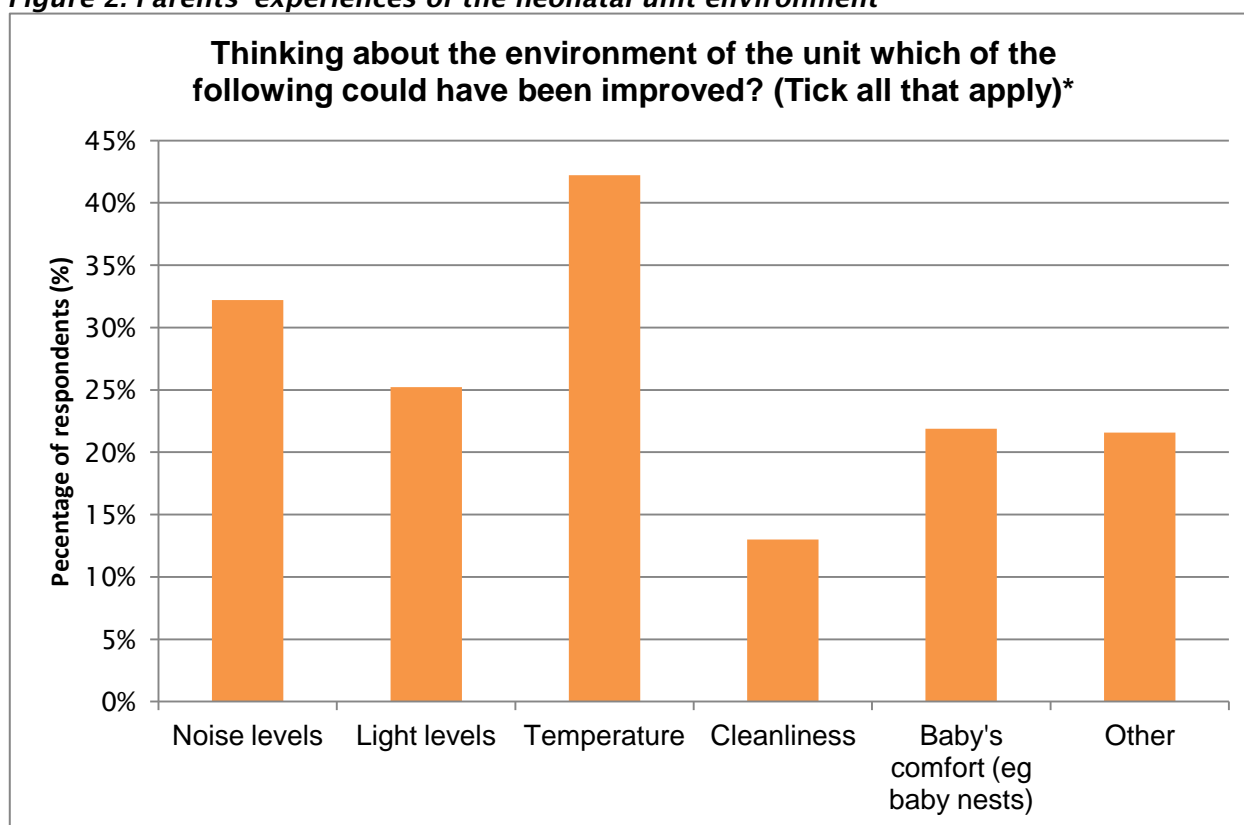
The survey showed a large variation across units with regards to the provision of somewhere for children to play when their parents are visiting their sibling in the unit.

The proportion of parents who said that there was nowhere for their children to play when visiting the unit ranged between 0% and 92% across units.

Sixty six percent of parents said that there was always, or nearly always, enough space for them to sit alongside their baby's cot in the unit. However, one third of parents said that there was only enough space to sit alongside their baby's cot 'sometimes' (31%) or that there was 'never' enough space (3%). Of those parents whose baby was discharged from a Special Care Baby Unit, a significantly higher proportion said that there was always enough space for them to sit alongside their baby's cot (69%) when compared with those parents whose babies were discharged from a Local Neonatal Unit (64%) or Neonatal Intensive Care Unit (65%). The lack of space in the units providing higher level care may partly be explained by the increased amount of machines and monitors used in such units to care for the babies.

The survey asked parents if there were any aspects of the neonatal unit's environment that could have been improved. Most parents (63%) said that no improvements were needed. Of the 37% of parents who did think one or more improvements could be made to the unit's environment, the temperature and noise levels were the more commonly ticked options (Figure 2)

Figure 2: Parents' experiences of the neonatal unit environment



***Please note:** the 63% of parents that ticked 'no improvements were needed' have been excluded from this analysis and chart.

Transfers to another unit

Parents' have previously reported practical difficulties if their baby was transferred to another hospital for care, such as additional financial costs, and found it stressful to lose the continuity of care from the previous hospital.⁴ One of the markers of good practice outlined in the toolkit for high-quality neonatal services is that a mother and her baby are cared for in the same hospital.²

Toolkit for high-quality neonatal services

3.13 Every effort is made to keep a mother and her baby/babies in the same hospital during their respective admissions.

Around one in ten parents (13%) said that their baby was transferred to a neonatal unit at a different hospital. Of those parents who said that their baby was transferred, one third (33%) said that they were cared for in a separate hospital to their baby. There were no significant difference in the proportions of respondents reporting that this happened by the 'type' of unit their baby was discharged from (i.e. Special Care Baby Units, Local Neonatal Units, and Neonatal Intensive Care Units).

The importance of informing parents about the transfer service and providing information about the unit to which a baby is being transferred has been recognised.²

Toolkit for high-quality neonatal services

3.8 Written information is available to all users of the service to permit early and effective communication with parents covering at least:

- Transfer service and repatriation
- Services to which a baby is being transferred, including a named contact and telephone number

The survey showed that whilst the majority of parents (84%) said that staff clearly explained to them why their baby was being transferred to a different hospital, a smaller proportion (62%) said they were definitely given enough information about the hospital/unit where their baby was being transferred to. The survey highlighted other areas where parents' experiences of their baby being transferred to a different hospital could be improved:

- A relatively large proportion felt they were not given enough warning by staff that their baby was being transferred: 23% said they were only given enough warning 'to some extent' and 18% said they were not given enough warning at all.
- Around a quarter of parents (29%) also felt that the staff in the unit where their baby was transferred were only aware of the previous care their baby had received 'to some extent' with 9% reporting that staff were not aware at all.

Discharge from the unit

Principle 7 of the Bliss Baby Charter states that discharge planning should be facilitated and co-ordinated from admission to discharge to ensure both the baby and family receive appropriate care and access to resources. It is reasoned that discharge should be a seamless and supported journey from the unit to home.⁶ The toolkit for high-quality neonatal services outlines a number of markers of good practice to ensure the 'safe and effective' discharge of a baby; those that are covered by the parents' survey are outlined below.

Toolkit for high-quality neonatal services

3.15 Health and social care plans are coordinated to enable the safe and effective discharge of a baby:

- Parents are involved in multi-disciplinary discharge planning from the point of admission and plans are continually reviewed
- Families have appropriate information and training before being discharged home
- Parents have access to accommodation so they can be with their baby and develop confidence in day-to-day care prior to discharge

Offering overnight accommodation to parents in preparation for their baby's discharge can help parents to develop confidence in the day-to-day care of their baby.⁶ Most parents (80%) said they were offered accommodation overnight at the hospital before their baby came home. Only 4% of parents said that there were not offered overnight accommodation before their baby's discharge but would have liked it, although more than a quarter of parents (28%) reported this at the poorest performing unit for this question. As perhaps expected, a significantly higher proportion of parents said that they were offered overnight accommodation before discharge if their baby had stayed in the unit for a longer length of time (Appendix 6).

Three quarters of parents (75%) said they definitely felt prepared for their baby's discharge from neonatal care (ranging between 57% and 95% across units), although 22% reported that they only felt prepared 'to some extent'. Higher proportions of parents said they definitely felt prepared for their baby's discharge if their baby was born at a later gestational age, had a shorter length of stay in the unit and was discharged from a Special Care Baby Unit (Appendix 6). For example, of those parents whose baby was born at 38 weeks gestation or later, 78% said they definitely felt prepared for their baby's discharge home compared with 72% of parents whose baby was born at 37 weeks gestation or earlier.

Only 9% of parents said that their baby required some special equipment when they were discharged from the unit. Of these parents, the majority (78%) said that they were 'definitely' given enough information and guidance on using the equipment when their baby left the unit.

The survey showed that parents would have liked to have been given more information on what to expect in terms of their baby's progress and recovery. Almost one third of parents (32%) said they were only given enough information 'to some extent' whilst 15% said they were not given enough information on this at all. There was a large variation in parents' experience of being given this information across units; at the best performing unit for this question (i.e. scored 86 out of 100), 77% of parents said that they were definitely given enough information about what to expect in terms of their baby's progress, compared with just 32% of parents at the poorest performing unit for this question.

Care and support at home

Previous research with parents has shown the importance of providing on-going support from the neonatal unit at home following the baby's discharge.⁴ Both the toolkit for high-quality neonatal services and the NICE quality standard for neonatal care recognise that the baby and family have ongoing needs at home and include measures to ensure a smooth transition from hospital to community care:

NICE Specialist Neonatal Care Quality Standard

7) Babies receiving specialist neonatal care have their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care.

Toolkit for high-quality neonatal services

3.16 The ongoing care of babies and families discharged from neonatal services is provided according to the needs of the baby and in a manner that facilitates a smooth transition home

The care and support provided to parents once their baby had been discharged from the neonatal unit was highlighted in the 'summary of findings' as one of the main areas of the survey where parents reported the least positive experiences.

After their baby arrived home, 58% of parents said they had some contact with neonatal staff and the majority of these parents (24%) said that this contact was from their baby having a follow-up hospital appointment. A relatively small proportion of parents said that staff contacted them by telephone (19%) or visited them at home (15%) following discharge and almost one in ten (9%) said they did not have any contact with neonatal staff but would have liked this.

Almost all parents (96%) said they saw a health visitor after their baby was discharged from the neonatal unit. A relatively large proportion of these parents said that the health visitor did not have enough information about the development of babies who had received neonatal care: 35% said the health visitor only had this information 'to some extent' and 26% said the health visitor did not have enough information. This finding supports the recommendation made by the POPPY research project for training for health visitors and GPs in pre-term baby issues and the effects for families. This previous research highlighted that visits from health visitors with specialised knowledge in premature babies was highly valued by parents.⁴

The survey asked parents if they got enough support overall from health professionals after their baby arrived home. Only 58% of parents reported that they definitely got enough support. Almost one third of parents (32%) said they only got enough support 'to some extent', while 10% said they did not get enough support from health professionals

once their baby had arrived home. The proportion of parents who reported that they definitely got enough support from health professionals at home ranged between 37% and 76% across units.

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Appendix 1: Questionnaire development

This section outlines the main stages involved in developing the questionnaire used in the 2010-2011 Parents' Neonatal Survey.

Literature review and consultation

A list of survey topic areas was produced from a review of recent research studies, policy and quality standards documents on neonatal care. This list aimed to identify the areas of importance to parents and those issues that should come within the scope of this survey. Representatives from Bliss, Picker Institute Europe and a number of the Neonatal Networks attended a working group meeting in February 2010 to discuss and refine the proposed topic areas/issues to be covered in the questionnaire. Bliss also provided feedback on these issues from their parent representatives.

Many of the representatives from networks suggested extra subject areas that could be included in the questionnaire, although it was recognised that the questionnaire should not become too lengthy. It was agreed that the focus of the survey was to highlight key areas of good practice and where improvements were needed, and that more detailed investigations could be undertaken by networks/units at a later stage into particular issues raised by the survey findings.

The consultation with Bliss and the networks highlighted the importance of capturing the experiences of parents whose babies were transferred to different neonatal units. Whilst the questionnaire focused on examining parents' experiences of the neonatal unit that their baby was discharged from, it was recognised that the questionnaire should also allow parents to provide feedback on another unit if this is where their baby spent more time. Therefore, a section was included towards the end of the questionnaire containing a shortened set of the same questions which parents could complete about another neonatal unit where their baby spent more time.

Focus Groups

Four focus groups were conducted with parents whose baby had been cared for in a neonatal unit in the last twelve months. The aim of these focus groups was to explore parents views and experiences of the neonatal care their baby received in hospital and afterwards, to inform the development of the questionnaire.

The group discussions covered the parents 'journey' through neonatal care, from birth to admission and discharge from the unit in addition to care at home. The broad topic areas covered were:

- Organisation of care
- Parents' involvement in care
- Communication, information and support
- Quality of care and facilities

The groups were moderated by a senior researcher from Picker Institute Europe. The participants were recruited by Bliss via two of the neonatal networks. Two focus groups were conducted in London; one in Leeds and one in Birmingham. Participation from a mixture of mothers and fathers, and parents from different ethnic groups was aimed for.

Parents who had experienced different levels of neonatal care and who had experienced a transfer were also recruited for participation in the groups.

A total of 27 parents took part in the focus groups, 23 mothers and 4 fathers. Each focus group lasted approximately one and a half hours and was audio recorded. As most parents had their baby with them, the noise levels in the groups was high, making transcription of the audio tape potentially difficult. The facilitator therefore used a flip chart and participants were also asked to write on post it notes. The flip chart notes and post it notes were later written up and the recordings transcribed, taking care to remove any information that could identify individuals.

The focus group participants were very motivated and willing to talk about their experiences. All parents praised the skill and expertise of staff and the speed with which they responded to their babies' health crises. Parents' experiences varied widely, highlighting differences in the way hospitals organised care and treatment during the babies' journey through neonatal care. The main gaps identified by parents in the care received were information provision, sensitivity and ongoing emotional support.

Cognitive testing

Fifteen cognitive interviews with parents whose baby had been in neonatal care were conducted in June 2010 in the following locations: London, Leeds, Gloucestershire and the West Midlands. The interviewees were recruited by Bliss and parents were given a gift voucher to thank them for their time.

The purpose of the cognitive interviews was to test the relevance and validity of the questionnaire. The participants were asked to read the instructions on the front of the questionnaire and to answer the questions. They were asked whether the instructions were clear and easy to understand, and were encouraged to comment on their thought processes whilst completing the questionnaire. The researchers probed throughout the interviews to assess the interviewees understanding of the questions and to ensure that the response options were appropriate. Interviewees were also asked if any issues of importance to them had been omitted from the questionnaire.

The questionnaire was tested in three stages, with revisions being made to the questionnaire after each stage including amendments to question wording, the addition or deletion of response options and changes to the layout of the questionnaire.

Appendix 2: Participating neonatal units

Network	Hospital Neonatal Unit
Bedfordshire and Hertfordshire Neonatal Network	Bedford Hospital
	Lister Hospital, Stevenage
	Luton and Dunstable Hospital
	Queen Elizabeth II Hospital, Welwyn Garden City
	Watford Hospital
Cheshire and Merseyside Neonatal Network	Airedale General Hospital
	Arrowe Park Hospital, Wirral
	Countess of Chester
	Leighton Hospital, Crewe
	Liverpool Women's
	Macclesfield District General Hospital
	Ormskirk Hospital
	Warrington Hospital
	Whiston Hospital
Essex Neonatal Network (East of England)	Basildon Hospital
	Broomfield Hospital (formerly St John's, Chelmsford)
	Colchester Hospital
	Darent Valley Hospital
	Princess Alexandra Hospital Harlow
	Southend Hospital
Kent and Medway Neonatal Network	Maidstone District General
	Medway Maritime Hospital
	Pembury Hospital
	Queen Elizabeth Hospital, Margate
	William Harvey Hospital, Ashford
Lancashire and Cumbria South Neonatal Network	Blackpool Victoria Hospital
	Furness General Hospital
	Lancashire Women & Newborn Centre (formerly Royal Blackburn Hospital & Burnley General Hospital)
	Royal Lancaster Infirmary
	Royal Preston Hospital

London Perinatal and Neonatal Networks	Barnet Hospital
	Chase Farm Hospital
	Chelsea & Westminster Hospital
	Ealing Hospital
	Epsom General Hospital
	Homerton Hospital
	King George Goodmayes Hospital
	Croydon University Hospital (formerly Mayday Hospital)
	Newham General Hospital
	North Middlesex Hospital
	Queens Hospital, Romford
	Royal Free Hospital
	Royal London Hospital
	St George's Hospital
	St Helier Hospital
	St Thomas' Hospital
	Whipps Cross Hospital
Midlands Central Newborn Network	George Eliott Hospital, Nuneaton
	Kettering General Hospital
	Manor Hospital, Walsall
	Northampton General Hospital
	Queen's Hospital Burton on Trent
	Walsgrave Hospital Coventry
	Warwick Hospital
Norfolk, Suffolk and Cambridgeshire Neonatal Network	Addenbrooke's Hospital, Cambridge
	Hinchingbrooke Hospital, Huntingdon
	Ipswich Hospital
	James Paget Hospital, Great Yarmouth
	Norfolk and Norwich University Hospital
	Peterborough Maternity Unit
	Queen Elizabeth Hospital, King's Lynn
	West Suffolk Hospital, Bury St Edmonds

Northern Neonatal Network	Cumberland Infirmary, Carlisle
	Darlington Memorial Hospital
	South Tees Hospital NHS Foundation Trust
	Queen Elizabeth Hospital, Gateshead
	Royal Victoria Infirmary (Newcastle)
	South Tyneside District General Hospital
	Sunderland Royal Hospital
	University Hospital of North Tees
	University of Durham Hospital
	Wansbeck General, Ashington
	West Cumberland, Whitehaven
South Central Neonatal Network	Basingstoke and North Hampshire Hospital
	Dorset County Hospital, Dorchester
	Horton Hospital, Banbury
	John Radcliffe Hospital, Oxford
	Milton Keynes General Hospital
	Poole Hospital
	Princess Anne Hospital
	Queen Alexandra Hospital
	Royal Berkshire Hospital, Reading
	Royal Hampshire County Hospital
	Salisbury District Hospital
	St Mary's Hospital, Isle of Wight
	St Richard's Hospital
	Stoke Mandeville Hospital, Aylesbury
	Wexham Park Hospital, Slough
South West Midlands Newborn Network	Birmingham Heartlands Hospital
	Birmingham Women's Hospital
	City Hospital, Birmingham
	County Hospital, Hereford
	Good Hope Hospital
	Sandwell General Hospital
	Worcestershire Royal Hospital

Staffordshire, Shropshire and Black Country (SSBC) Neonatal Network	Alexandra Hospital, Redditch
	New Cross Hospital, Wolverhampton
	Royal Shrewsbury Hospital
	Russells Hall Hospital
	Stafford General Hospital
	University Hospital of North Staffordshire
Surrey and Sussex Neonatal Network	Conquest Hospital, Hasting, East Sussex
	East Surrey, Redhill
	Eastbourne Hospital
	Frimley Park
	Princess Royal, Haywards Heath
	Royal Surrey, Guildford
	Royal Sussex, Brighton
	St Peter's Hospital, Chertsey
	Worthing Hospital
Trent Perinatal Network	Derbyshire Children's Hospital
	King's Mill Hospital
	Lincoln County Hospital
	Nottingham City Hospital
	Pilgrim Hospital, Boston
	Queen's Medical Centre University Hospital
	University of Hospitals Leicester NHS Trust
Yorkshire Neonatal Network	Bradford Royal Infirmary
	Calderdale Royal Hospital
	Dewsbury and District Hospital
	Harrogate District Hospital
	Hull Royal Infirmary
	Leeds Neonatal Service
	Pontefract General Infirmary
	Scarborough General Hospital

Appendix 3: Response rates

Overall response rates

A total of 19,305 questionnaires were mailed to parents and 9,442 were returned completed (Table 1). The overall response rate to the pilot survey was **50.4%** after adjusting for questionnaires returned undelivered, sent to parents who were ineligible to take part in the survey (e.g. baby did not stay in a neonatal unit, baby stayed in the unit for less than 24 hours) or to families where the mother or baby had died following discharge. The adjusted response rates ranged between 42% and 57% across the 19 neonatal networks and between 32% and 73% across units.

Table 1: Overall response rate

Outcome of sending questionnaire	Returned useable questionnaire	9442
	Returned undelivered or parent moved house	473
	Mother or baby died	4
	Too ill, opted out or returned blank questionnaire	186
	Parent not eligible to fill in questionnaire	86
	Questionnaire not returned - reason not known	9114
Base		19305
Adjusted base		18742
Adjusted response rate		50.4%

The response rates for each wave of the survey are shown in Table 2. The response rate was highest for the last wave of the survey which is most likely because the majority of units submitted their samples to the Picker Institute on time in this wave so the first mailings could be sent out in November for the majority of units, thereby reducing the delays in parents receiving the questionnaire following their baby's discharge from the unit.

Table 2: Overall response rate by survey 'wave'

Wave	Sampling period	First mailing sent out	Number of respondents	Adjusted response rate
1	April-June 2010	August-October 2010	2712	50.3%
2	July-September 2010	November 2010-January 2011	3196	47.1%
3	October-December 2010	February-March 2011	3534	53.9%
National			9442	50.4%

Demographics of responders and non-responders

Most units supplied the age and ethnic group of the parents included in the sample. Using this information and the outcome of each sample member (i.e. whether they returned a completed questionnaire or not), the response rates were calculated for age and ethnic groups. It is important to compare the response rates for different demographic groups of responders and non-responders to the survey, as the responders may not be representative of all those sampled.

Age

The response rates increased with age as completed questionnaires were received from:

- 36.6% of parents aged 16-27 years
- 51.2% of parents aged 28-31 years
- 58.8% of parents aged 32-35 years
- 63.3% of parents aged 36 and over

The differences in response rates between age groups were significant indicating that the achieved sample was not representative of some age groups (Table 2).

Table 2: Response rate by age group

		Did not respond opted out	Responded	Total
Age group	1 16-27	3712	2141	5853
		63.4%	36.6%	100.0%
	2 28-31	2056	2153	4209
		48.8%	51.2%	100.0%
	3 32-35	1624	2319	3943
		41.2%	58.8%	100.0%
	4 36 and over	1586	2732	4318
		36.7%	63.3%	100.0%
Total		8978	9345	18323
		49.0%	51.0%	100.0%

$\chi^2=844$, $df=3$, $p>0.001$

Ethnic group

The response rates by ethnic group are shown in Table 3. There were significant differences in response rates between the groups. Whilst in other national patient surveys, the response rates are higher for those from White groups when compared with Black and minority ethnic groups, in this survey a higher response rate was actually evident for the 'Chinese or other ethnic groups' (57%) when compared with white respondents (55%). However, the response rates for Asian/Asian British and Black/Black British parents were lower (41% and 42% respectively).

This analysis has shown that one of the limitations to the neonatal survey is that, in common with many other research studies and patient surveys, younger people and those from some minority ethnic groups were less likely to participate.⁷

Table 3: Response rate by ethnic group

		Did not respond opted out	Responded	Total
Ethnic group	1 White	6600	7906	14506
		45.5%	54.5%	100.0%
	2 Mixed	134	151	285
		47.0%	53.0%	100.0%
	3 Asian or Asian British	1127	793	1920
		58.7%	41.3%	100.0%
	4 Black or Black British	490	354	844
		58.1%	41.9%	100.0%
	5 Chinese or Other Ethnic Group	180	235	415
		43.4%	56.6%	100.0%
Total		8531	9439	17970
		47.5%	52.5%	100.0%

$\chi^2 = 160$, $df=4$, $p>0.001$

Appendix 4: Creation of question domains

Excluded questions

To avoid problems in generating site level domain scores, questions were excluded from the analysis if the overall item response rate was less than 70%. This threshold was chosen as it appeared to represent a natural 'step' in the distribution of item response rates. In total, 17 items (24%) were excluded:

Items excluded from the analysis due to low item response rates.

Q	Question wording	Item resp. rate
A2	Before your baby was born, were you given the chance to visit the neonatal unit?	28%
A3	Before your baby was born, did a member of staff from the neonatal unit talk to you about what to expect after the birth?	31%
B3	Were you given a photograph of your baby?	65%
B6	How long did you wait before a member of staff came to talk to you about your baby's condition and treatment?	58%
C2	Were you and your baby ever cared for in separate hospitals?	12%
C4	Did staff clearly explain to you why your baby was being transferred to a different hospital?	12%
C5	Did you feel you were given enough warning by staff that your baby was going to be transferred?	11%
C6	In your opinion, were staff in the new unit fully aware of the care your baby had received so far?	12%
C7	Were you given enough information about the hospital/unit where your baby was being transferred (such as location and facilities)?	12%
E16	If you bottle fed your baby (formula milk) were you given enough support to do this from neonatal staff?	59%
F8	If you had your other children with you when visiting the unit, was there somewhere they could play?	40%
G2	If you needed help understanding written or spoken English, was information given in a language you could understand?	10%
G5	If your baby had any surgery, did a member of staff explain the operation and its outcome in a way you could understand?	8%
G7	Were you offered emotional support or counselling services?	43%
H4	Were you offered accommodation overnight at the hospital before your baby came	55%

	home?	
H7	Were you given enough information and guidance on using the equipment when your baby left the neonatal unit?	9%
H9	Follow-up contact with the neonatal unit	44%

Factor analysis

The variables listed above were excluded from the dataset and mean scores for the remaining items were computed for each participating site (i.e. neonatal unit). Mean scores were computed based on weighted data to ensure a balanced case-mix between sites. The site-level mean scores of the remaining 56 items were then subjected to a factor analysis. Varimax rotation was used to clearly divide items between factors.

The rotated analysis included 13 components with Eigenvalues of greater than one. In total these accounted for around 73% of the overall variance. Each of the first seven factors accounts for $\geq 5\%$ of the total variance, with 52% accounted for by the first seven factors collectively. Consequently, we focus only on the first seven factors[‡].

The rotated component matrix was inspected to identify items with high loadings to particular components: this is shown in figure 3, below. Items with factor loadings of ≥ 0.5 were extracted for further analysis.

[‡] Note that an alternative interpretation could be made using a smaller number of factors, since the scree plot appears to show a distinct elbow after three to four factors. This may be useful if shortened questionnaires are required for future use.

Rotated component matrix showing high loadings

Q	Wording	Component												
		1	2	3	4	5	6	7	8	9	10	11	12	13
B4	After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?	.336	.048	-.143	.070	-.121	.297	.259	.139	-.091	.107	.073	-.104	-.153
B5	After the birth, did a member of staff come to talk to you about your baby's condition and treatment?	.195	.522	.018	.306	.019	.263	.203	-.102	-.034	.014	-.092	.209	-.328
B7	After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?	.065	.220	.184	.109	.134	.162	-.011	.059	-.047	.155	.725	.032	-.220
B8	After your baby was admitted to the neonatal unit, was your partner or companion able to see your baby as soon as they wanted?	.150	-.053	.151	.037	.101	-.102	.074	-.005	.067	-.013	.805	.012	.199
B9	After you gave birth, was a partner or family member allowed to stay with you overnight?	.020	.268	-.064	.150	.005	-.012	.009	.044	.122	.507	.399	-.216	-.075
B10	When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?	.384	.583	.109	.197	.179	-.020	.156	.336	.174	.158	.104	.156	-.041
B11	When your partner or companion first visited the unit, were they able to speak to a doctor or nurse about your baby's condition as soon as they wanted?	.336	.644	.081	.181	.170	.033	.065	.311	.155	.149	.124	.055	.088
B12	When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)?	.337	.699	-.002	-.095	.017	.209	.164	.059	.133	.064	.162	.067	-.023
B13	When you first visited your baby, was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?	.446	.499	-.060	.261	.180	.080	.169	.098	.217	.148	.004	.261	-.109
B14	When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?	.125	.763	-.108	-.291	-.200	.018	.138	.096	-.020	-.035	-.018	-.016	.129
D1	When you visited the unit, did the staff caring for your baby introduce themselves to you?	.525	.221	.054	.188	-.009	.120	.011	.111	.588	.083	.058	-.010	-.035
D2	Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?	.253	.231	.075	.007	.043	.069	-.095	.061	.734	.022	.045	-.078	.207
D3	Did staff keep you up to date with your baby's condition and progress?	.618	.421	.211	.105	.015	.063	.031	.222	.342	.088	-.076	.049	-.067
D4	Were you able to talk to staff on the unit about your worries and concerns?	.686	.309	.301	.190	.129	.147	.051	.190	.200	.080	-.008	-.008	.024

Q	Wording	Component												
		1	2	3	4	5	6	7	8	9	10	11	12	13
D5	Were you able to speak to a doctor about your baby as much as you wanted?	-.015	.462	.224	.281	-.108	.178	.031	.597	.091	-.074	.035	.018	.128
D6	Were the nurses on the unit sensitive to your emotions and feelings?	.733	.140	.112	.124	.191	.191	.118	.049	.362	.102	.019	.056	.123
D7	Were the doctors on the unit sensitive to your emotions and feelings?	.368	.146	-.137	.028	.213	.034	.124	.681	.086	-.013	-.004	-.030	-.048
D8	In your opinion, was important information about your baby passed on from one member of staff to another?	.705	.224	.168	.051	.132	.116	.120	.339	.092	.020	.082	.175	.046
D9	Did staff give you conflicting information about your baby's condition or care?	.662	-.108	-.056	-.143	.043	-.194	-.158	.124	-.039	-.004	.343	.169	.023
D10	As far as you know, did staff wash or clean their hands before touching your baby?	.550	.132	-.086	-.046	.105	.119	.235	-.239	.096	.072	-.087	-.409	.040
D11	Did staff refer to your baby by his/her first name?	.600	.009	-.132	.417	.346	-.002	-.016	-.143	.035	.182	.056	.132	.040
D12	Overall, did staff treat you with respect and courtesy?	.766	.082	.195	.116	.106	.166	.015	.019	.256	.023	.068	-.058	.134
D13	Overall, did you have confidence and trust in the staff caring for your baby?	.856	.150	.070	.062	.093	.034	.081	.063	.060	.114	.036	-.072	.025
E1	Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	.092	.121	.760	.145	.286	.123	.037	.053	-.217	.081	.008	-.063	.015
E2	Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?	.350	.133	.588	.070	.345	-.044	.052	-.038	-.231	.190	.096	.032	.187
E3	Were you encouraged to touch, hold and comfort your baby?	.118	.000	.799	-.020	-.085	.203	-.065	.062	.200	.013	.122	.072	.044
E4	Did you have as much 'kangaroo care' (skin- to-skin contact) with your baby as you wanted?	-.045	-.148	.740	.005	-.040	.078	.190	.029	.304	-.080	.191	.187	-.016
E5	Did the doctors and nurses include you in discussions about your baby's care and treatment?	.255	.204	.254	.619	.005	.127	.267	.340	.099	.085	.089	.101	-.023
E6	Were you told about any changes in your baby's condition or care?	.510	.374	.214	.290	.169	.028	.117	.348	.119	-.005	-.026	.105	.103
E7	When a ward round was taking place, were you allowed to be present when your baby was being discussed?	.219	-.084	-.030	.839	.081	-.006	.085	.078	.044	.117	.051	.065	.117

Q	Wording	Component												
		1	2	3	4	5	6	7	8	9	10	11	12	13
E8	Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	.460	.106	.102	.367	.354	.051	.134	-.032	.000	.205	.050	.383	.051
E9	Overall, did staff help you feel confident in caring for your baby?	.659	.250	.214	.155	.211	.163	.148	.147	.182	.111	.016	.189	.098
E10	If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?	.292	.231	.219	.030	.505	.468	.081	.051	.136	.158	.240	.133	.103
E11	Were you given the equipment you needed, such as a breast pump and sterilisation equipment?	.171	.047	.283	-.040	.665	.281	.041	.004	.092	.283	.079	.127	.046
E12	Were you given enough privacy for expressing milk for your baby?	.016	.010	.153	.016	.126	.830	.029	.056	-.051	.126	-.120	-.026	.119
E13	Were there facilities on the neonatal unit for the storage of breast milk?	.234	-.119	-.075	.063	.742	.030	.041	.084	.009	.001	.058	-.061	.060
E14	If you wanted to breastfeed your baby were you given enough support to do this from neonatal staff?	.281	.268	.246	.045	.409	.428	.057	.176	.177	.072	.148	.114	.025
E15	Were you given enough privacy for breast feeding your baby?	.223	.208	.119	.107	.137	.785	.092	.011	.180	-.029	.086	.090	.024
F1	Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?	.489	.045	.102	.518	-.058	.225	.296	.163	.064	-.014	.144	-.034	.110
F2	What improvements were needed?	.672	.143	-.269	.163	-.009	.169	.037	-.026	-.216	.047	.069	.012	.054
F3	Was there enough space for you to sit alongside your baby's cot in the unit?	.195	-.011	.001	.238	-.216	.279	.231	.244	-.087	.372	-.133	.172	-.076
F4	In your opinion, was there adequate security on the neonatal unit?	.392	.149	-.231	.165	-.130	.153	.338	-.038	-.314	.066	.061	.240	.313
F5	If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?	.158	.037	.170	.315	.270	.213	.233	-.020	.004	.662	.162	-.058	-.107
F6	Were you able to visit your baby on the unit as much as you wanted to?	.244	.095	.271	.385	.444	.132	-.016	.116	-.250	-.098	.108	-.228	.005
F9	Were you able to contact the unit by telephone whenever you needed to?	.574	.246	-.086	.247	.245	.030	-.160	-.087	-.161	.294	-.088	.052	.233
G1	Were you given enough written information to help you understand your baby's condition and treatment?	.204	.387	.195	.154	.073	.238	.463	.119	.174	-.026	.098	.282	.212

Q	Wording	Component												
		1	2	3	4	5	6	7	8	9	10	11	12	13
G3	When you asked questions about your baby's condition and treatment, did you get answers you could understand?	.586	.209	.124	.161	.245	.109	.185	.417	.030	-.025	.092	-.018	-.080
G4	Did a member of staff explain the purpose of any tests your baby had in a way you could understand?	.631	.050	.149	.123	.329	.049	.212	.308	-.035	.071	.121	.026	-.089
G8	Were you given information about any help you could get with travelling expenses, parking costs or food vouchers?	.214	.013	.034	-.084	.105	.039	-.026	-.019	.036	.694	-.016	.162	.312
G9	Did staff give you any information about parent support groups, such as Bliss or other local groups?	.173	.040	.115	.140	.117	.145	.099	.005	.147	.121	.008	.030	.788
H2	In your opinion, was your baby's stay in neonatal care...	.466	.162	.278	.078	-.056	-.081	-.155	.400	-.100	.165	.002	.110	.085
H5	Did you feel prepared for your baby's discharge from neonatal care?	.072	.210	.110	.064	.016	.072	.215	.027	-.050	.040	-.005	.703	.036
H8	Were you given enough information on what to expect in terms of your baby's progress and recovery?	.217	.253	.131	.049	-.035	.209	.512	.406	.150	.061	.237	.239	-.115
H11	If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?	-.117	.247	.062	.059	.017	.079	.766	.066	-.116	-.075	.107	.154	.018
H12	Overall, after your baby arrived home, did you get enough support from health professionals?	.249	.046	-.001	.175	.151	-.036	.768	.005	-.003	.213	-.150	-.012	.084

Rotated components

Factor loadings, correlations, and other evidence were reviewed to further refine each of the rotated components. Only the first seven factors were considered in detail. Additionally, a scale reduction approach was only followed for those factors with four or more factors strongly loaded: factors one, two, and three.

Factor one – Trust and confidence in staff

Component 1 loadings

D1	When you visited the unit, did the staff caring for your baby introduce themselves to you?	.525
D3	Did staff keep you up to date with your baby's condition and progress?	.618
D4	Were you able to talk to staff on the unit about your worries and concerns?	.686
D6	Were the nurses on the unit sensitive to your emotions and feelings?	.733
D8	In your opinion, was important information about your baby passed on from one member of staff to another?	.705
D9	Did staff give you conflicting information about your baby's condition or care?	.662
D10	As far as you know, did staff wash or clean their hands before touching your baby?	.550
D11	Did staff refer to your baby by his/her first name?	.600
D12	Overall, did staff treat you with respect and courtesy?	.766
D13	Overall, did you have confidence and trust in the staff caring for your baby?	.856
E6	Were you told about any changes in your baby's condition or care?	.510
E9	Overall, did staff help you feel confident in caring for your baby?	.659
F2	What improvements were needed?	.672
F9	Were you able to contact the unit by telephone whenever you needed to?	.574
G3	When you asked questions about your baby's condition and treatment, did you get answers you could understand?	.586
G4	Did a member of staff explain the purpose of any tests your baby had in a way you could understand?	.631

Cronbach's Alpha = 0.937

Component one appeared to reflect an underlying construct relating to emotional and relational aspects of care and demonstrated exceptionally high scale reliability with 16 items included.

Several items can be removed from this factor to construct a shortened domain:

- D1 is weakly loaded to this factor but is more strongly loaded to component nine, suggesting that it better fits a different construct.

- D10, E6, and F9 are also weakly loaded to the factor and should be removed.
- D4 and D6 are strongly correlated with D12 ($r=0.720$, $r=0.804$) and D13 ($r=0.712$, $r=0.726$) respectively. One of these pairs of questions should be removed: given the high item loadings of D12 and D13, retain these.
- D12 and D13 are highly correlated ($r=0.742$) and both are overall questions: drop D12.
- D8 is strongly correlated with several other items: D4 ($r=0.716$), D6 ($r=0.706$), E9 ($r=0.751$), and G3 ($r=0.711$). It therefore lacks uniqueness and can be removed.
- F2 is highly correlated with D13 ($r=0.622$) as is potentially problematic for use in a domain (as the 'other' response option is excluded from the analysis) – therefore drop F2.
- G3 and G4 are strongly correlated ($r=0.734$) and superficially appear to cover very similar topics. Given weak item loading of G3, drop G3 and retain G4.

This leaves us with a six item domain comprising:

Q	Question wording
D3	Did staff keep you up to date with your baby's condition and progress?
D9	Did staff give you conflicting information about your baby's condition or care?
D11	Did staff refer to your baby by his/her first name?
D13	Overall, did you have confidence and trust in the staff caring for your baby?
E9	Overall, did staff help you feel confident in caring for your baby?
G4	Did a member of staff explain the purpose of any tests your baby had in a way you could understand?

Cronbach's Alpha = 0.828

The correlation between site-level scores for this factor based on the full 16 items and the shortened six item domain was $r=0.960$, indicating exceptionally high agreement between the two measures.

Factor two – Knowledge and information sharing

Component 2 loadings

B5	After the birth, did a member of staff come to talk to you about your baby's condition and treatment?	.522
B10	When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?	.583
B11	When your partner or companion first visited the unit, were they able to speak to a doctor or nurse about your baby's condition as soon as they wanted?	.644
B12	When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)	.699
B14	When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?	.763

Cronbach's Alpha = 0.811

Factor two appeared to reflect the quality of communication with and information from staff at the start of the neonatal episode.

- B10 and B11 were extremely strongly correlated ($r=0.871$). Although B11 had a higher loading it was applicable to fewer respondents, so remove B11 and retain B10.

This leaves a four-item domain comprising:

Q	Question wording
B5	After the birth, did a member of staff come to talk to you about your baby's condition and treatment?
B10	When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?
B12	When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)
B14	When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?

Cronbach's Alpha = 0.760

Unsurprisingly, the correlation between site-level scores for this factor based on the full five items and the shortened four item domain was very high ($r=0.990$), indicating exceptionally high agreement between the two measures.

Factor 3 – Active Care

Component 3 loadings

E1	Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	.760
E2	Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?	.588
E3	Were you encouraged to touch, hold and comfort your baby?	.799
E4	Did you have as much 'kangaroo care' (skin- to-skin contact) with your baby as you wanted?	.740

Cronbach's Alpha = 0.738

Factor three appeared to represent the extent to which staff on neonatal wards supported and encouraged new parents to be actively involved in caring for their children.

- Recommend retaining all items: E1 & E2 are strongly correlated, as are E3 and E4, but all items appear to have value for the domain.

Factor 4 – Empowered decision-making

Component 4 loadings

E5	Did the doctors and nurses include you in discussions about your baby's care and treatment?	.619
E7	When a ward round was taking place, were you allowed to be present when your baby was being discussed?	.839
F1	Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?	.518

Cronbach's Alpha = 0.653

Q	Question wording
E5	Did the doctors and nurses include you in discussions about your baby's care and treatment?
E7	When a ward round was taking place, were you allowed to be present when your baby was being discussed?
F1	Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?

Factor 5 – Privacy for breastfeeding

Component 5 loadings

E12	Were you given enough privacy for expressing milk for your baby?	.830
E15	Were you given enough privacy for breast feeding your baby?	.785

Cronbach's Alpha = 0.750

Q	Question wording
E12	Were you given enough privacy for expressing milk for your baby?
E15	Were you given enough privacy for breast feeding your baby?

Factor 6 – Co-ordinated discharge planning

Component 6 loadings

H8	Were you given enough information on what to expect in terms of your baby's progress and recovery?	.512
H11	If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?	.766
H12	Overall, after your baby arrived home, did you get enough support from health professionals?	.768

Cronbach's Alpha = 0.728

Q	Question wording
H8	Were you given enough information on what to expect in terms of your baby's progress and recovery?
H11	If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?
H12	Overall, after your baby arrived home, did you get enough support from health professionals?

Factor 7 – Interaction with doctors

Component 7 loadings

D5	Were you able to speak to a doctor about your baby as much as you wanted?	.597
D7	Were the doctors on the unit sensitive to your emotions and feelings?	.681

Cronbach's Alpha = 0.610

Q	Question wording
D5	Were you able to speak to a doctor about your baby as much as you wanted?
D7	Were the doctors on the unit sensitive to your emotions and feelings?

Table 1 below provides an overview of the seven domains mapped to the relevant quality standards for neonatal care.

Table 1: Question domains mapped to neonatal quality standards

Domains	Survey question	NICE Specialist Neonatal Care Quality Standard	DH Toolkit for High-Quality Neonatal Services	Bliss Baby Charter
Relationships with staff	D3. Did staff keep you up to date with your baby's condition and progress?	5a, 5b Encouraging parental involvement in decision-making processes and care	3.4 Decision making	2.1 Decision making
	D9. Did staff give you conflicting information about your baby's condition or care?	5b Encouraging parental involvement in care	3.4 Decision making	2.1 Decision making
	D11. Did staff refer to your baby by his/her first name?			1.1a Dignity and Privacy
	D13. Overall, did you have confidence and trust in the staff caring for your baby?			
	E9. Overall, did staff help you feel confident in caring for your baby?	5b Encouraging parental involvement in care	3.5 Parental involvement	5.6 Daily Cares
	G4. Did a member of staff explain the purpose of any tests your baby had in a way you could understand?	5a Encouraging parental involvement in decision-making processes	3.9 Written information	2.1d Decision making
Knowledge and information	B5. After the birth, did a member of staff come to talk to you about your baby's condition and treatment?	5a, 5b Encouraging parental involvement in decision-making processes and care		5.1 Introduction to unit

sharing	B10. When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?	5a, 5b Encouraging parental involvement in decision-making processes and care		2.1b Decision making
	B12. When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)		3.2 Introduction	5.1e Introduction to unit
	B14. When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?		3.2 Introduction	5.1b Introduction to unit
Active care	E1. Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	5b Encouraging parental involvement in care	3.5 Parental involvement	5.6a Daily Cares
	E2. Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?	5b Encouraging parental involvement in care	3.5 Parental involvement	5.6a Daily Cares
	E3. Were you encouraged to touch, hold and comfort your baby?	5b Encouraging parental involvement in care	3.5 Parental involvement	1.2a Dignity and Privacy
	E4. Did you have as much 'kangaroo care' (skin- to-skin contact) with your baby as you wanted?	5b Encouraging parental involvement in care	3.5 Parental involvement	1.3a Dignity and Privacy
Empowered	E5. Did the doctors and nurses include you in discussions about your baby's care and treatment?	5a Encouraging parental involvement in decision-making processes	3.4 Decision making	2.1h Decision making

decision making	E7. When a ward round was taking place, were you allowed to be present when your baby was being discussed?	5a Encouraging parental involvement in decision-making processes	3.4 Decision making	2.1a Decision making
	F1. Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?		3.6 Dignity and respect	1.1f Dignity and Privacy

Privacy for breastfeeding	E12. Were you given enough privacy for expressing milk for your baby?	6 Breastfeeding	3.1 Encourage breastfeeding	6.2b Breastfeeding
	E15. Were you given enough privacy for breast feeding your baby?	6 Breastfeeding	3.1 Encourage breastfeeding	6.2b Breastfeeding
Co-ordinated discharge planning	H8. Were you given enough information on what to expect in terms of your baby's progress and recovery?	7 Coordinated transition to community care	3.8 Information / / 3.15 Co-ordinated discharge	7.3a Baby's needs at home
	H11. If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?	7 Coordinated transition to community care	3.15 Co-ordinated discharge	7.1 Co-ordinated discharge plan
	H12. Overall, after your baby arrived home, did you get enough support from health professionals?	7 Coordinated transition to community care	3.15 Co-ordinated discharge	7.1 Co-ordinated discharge plan
Interaction with doctors	D5. Were you able to speak to a doctor about your baby as much as you wanted?	5a, 5b Encouraging parental involvement in decision-making processes and care		1.1f Dignity and Privacy
	D7. Were the doctors on the unit sensitive to your emotions and feelings?			

Appendix 5: Frequency tables for all questions

Before your baby was born

A1 Before your baby was born, did you know that they might need care in a neonatal unit?

	Number	Percentage
1 Yes	2972	32%
2 No	6200	68%
Total specific responses	9172	100%
Missing responses	64	

Answered by all

A2 Before your baby was born, were you given the chance to visit the neonatal unit?

	Number	Percentage
1 Yes	1022	41%
2 No, but I did not mind	976	38%
3 No, but I would have liked this	548	21%
Total specific responses	2546	100%
4 This was not possible due to medical reasons	401	
Missing responses	41	

Answered by those who knew their baby might need neonatal care

**A3 Before your baby was born, did a member of staff
 from the neonatal unit talk to you about what to
 expect after the birth?**

	Number	Percentage
1 Yes, definitely	1004	36%
2 Yes, to some extent	593	21%
3 No	1221	43%
Total specific responses	2818	100%
4 Don't know / Can't remember	135	
Missing responses	35	

Answered by those who knew their baby might need
 neonatal care

Admission to neonatal care

**B2 After the birth, were you able to touch your baby
 before s/he was taken to the neonatal unit?**

	Number	Percentage
1 Yes	6496	85%
2 No	1097	15%
Total specific responses	7593	100%
3 It was not possible due to medical reasons	1232	
Missing responses	411	

Answered by all

B3 Were you given a photograph of your baby?

	Number	Percentage
1 Yes	4004	46%
2 No, but I would have liked this	2012	23%
3 No, but I took a photograph myself	2676	31%
Total specific responses	8692	100%
4 I did not want a photograph taken	268	
Missing responses	276	

Answered by all

B4 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?

	Number	Percentage
1 Yes, and this bothered me	2812	32%
2 Yes, but I did not mind	2362	27%
3 No, I stayed in a separate room/area	3482	41%
Total specific responses	8656	100%
4 I was discharged from hospital	298	0%
Missing responses	282	0%

Answered by all

B5 After the birth, did a member of staff come to talk to you about your baby's condition and treatment?

	Number	Percentage
1 Yes	6561	78%
2 No	1861	22%
Total specific responses	8422	100%
3 Don't know / Can't remember	643	
Missing responses	171	

Answered by all

B6 How long did you wait before a member of staff came to talk to you about your baby's condition and treatment?

	Number	Percentage
1 Less than one hour	3145	59%
2 More than one hour but less than two	1101	20%
3 More than two hours but less than four	593	11%
4 Four hours or more	547	10%
Total specific responses	5386	100%
5 Don't know / Can't remember	1136	
Missing responses	78	

Answered by those who spoke to a member of staff after the birth

**B7 After your baby was admitted to the neonatal unit,
were you able to see your baby as soon as you
wanted?**

	Number	Percentage
1 Yes, staff took me	4672	66%
2 Yes, family took me	1594	23%
3 No	767	11%
Total specific responses	7033	100%
4 No, but this was not possible due to medical reasons	1898	
Missing responses	305	

Answered by all

**B8 After your baby was admitted to the neonatal unit,
was your partner or companion able to see your baby
as soon as they wanted?**

	Number	Percentage
1 Yes	8137	95%
2 No	404	5%
Total specific responses	8541	100%
3 No, but this was not possible for medical reasons	462	
4 No partner/companion was involved	130	
Missing responses	103	

Answered by all

B9 After you gave birth, was a partner or family member allowed to stay with you overnight?

	Number	Percentage
1 Yes	1352	19%
2 No	5951	81%
Total specific responses	7303	100%
3 This was not wanted or needed	1742	
Missing responses	191	

Answered by all

B10 When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?

	Number	Percentage
1 Yes, definitely	5947	65%
2 Yes, to some extent	2485	27%
3 No, I would have liked to have spoken to somebody earlier	690	8%
Total specific responses	9122	100%
Missing responses	114	

Answered by all

B11 When your partner or companion first visited the unit, were they able to speak to a doctor or nurse about your baby's condition as soon as they wanted?

	Number	Percentage
1 Yes, definitely	5910	66%
2 Yes, to some extent	2451	27%
3 No, but they would have liked to have spoken to somebody earlier	595	7%
Total specific responses	8956	100%
4 No partner/companion was involved	150	
Missing responses	130	

Answered by all

B12 When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents?

	Number	Percentage
1 Yes, definitely	5053	57%
2 Yes, to some extent	2383	27%
3 No	1379	16%
Total specific responses	8815	100%
4 Can't remember	310	
Missing responses	111	

Answered by all

B13 When you first visited your baby, was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?

	Number	Percentage
1 Yes, definitely	4725	54%
2 Yes, to some extent	2581	29%
3 No	1459	17%
Total specific responses	8765	100%
4 Don't know / Can't remember	276	
Missing responses	195	

Answered by all

B14 When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?

	Number	Percentage
1 Yes, definitely	6626	74%
2 Yes, to some extent	1316	15%
3 No	1013	11%
Total specific responses	8955	100%
4 Don't know / Can't remember	173	
Missing responses	108	

Answered by all

Being transferred to another unit

C1 Was your baby ever transferred (moved) to a neonatal unit at a different hospital?

	Number	Percentage
1 Yes	1131	13%
2 No, s/he stayed in the same hospital	7993	87%
Total specific responses	9124	100%
Missing responses	112	

Answered by all

C2 Were you and your baby ever cared for in separate hospitals?

	Number	Percentage
1 Yes	373	33%
2 No	753	67%
Total specific responses	1126	100%
Missing responses	11	

Answered by those whose baby was transferred to a different unit

C3 How many different hospitals did your baby stay in?

	Number	Percentage
1 Two	969	87%
2 Three	122	11%
3 Four or more	23	2%
Total specific responses	1114	100%
Missing responses	20	

Answered by those whose baby was transferred to a different unit

C4 Did staff clearly explain to you why your baby was being transferred to a different hospital?

	Number	Percentage
1 Yes, definitely	894	84%
2 Yes, to some extent	147	14%
3 No	24	2%
Total specific responses	1065	100%
4 An explanation was not needed	61	
Missing responses	14	

Answered by those whose baby was transferred to a different unit

C5 Did you feel you were given enough warning by staff that your baby was going to be transferred?

	Number	Percentage
1 Yes, definitely	607	59%
2 Yes, to some extent	236	23%
3 No	181	18%
Total specific responses	1024	100%
4 No, but the transfer(s) was an emergency	93	
Missing responses	21	

Answered by those whose baby was transferred to a different unit

C6 In your opinion, were staff in the new unit fully aware of the care your baby had received so far?

	Number	Percentage
1 Yes, definitely	727	69%
2 Yes, to some extent	277	25%
3 No	70	6%
Total specific responses	1074	100%
4 Don't know / Can't remember	55	
Missing responses	13	

Answered by those whose baby was transferred to a different unit

C7 Were you given enough information about the hospital/unit where your baby was being transferred (such as location and facilities)?

	Number	Percentage
1 Yes, definitely	662	62%
2 Yes, to some extent	316	29%
3 No	102	9%
Total specific responses	1080	100%
4 This information was not needed	50	
Missing responses	11	

Answered by those whose baby was transferred to a different unit

Staff on the neonatal unit

D1 When you visited the unit, did the staff caring for your baby introduce themselves to you?

	Number	Percentage
1 Yes, all of the staff introduced themselves	5099	56%
2 Some of the staff introduced themselves	3310	37%
3 Very few or none of the staff introduced themselves	607	7%
Total specific responses	9016	100%
4 Don't know / Can't remember	100	
Missing responses	120	

Answered by all

D2 Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?

	Number	Percentage
1 Yes	7826	86%
2 No	1276	14%
Total specific responses	9102	100%
Missing responses	134	

Answered by all

**D3 Did staff keep you up to date with your baby's
condition and progress?**

	Number	Percentage
1 Yes, always or nearly always	7188	79%
2 Yes, sometimes	1651	18%
3 No	287	3%
Total specific responses	9126	100%
Missing responses	110	

Answered by all

**D4 Were you able to talk to staff on the unit about
your worries and concerns?**

	Number	Percentage
1 Yes, always or nearly always	6857	76%
2 Yes, sometimes	1895	21%
3 No	268	3%
Total specific responses	9020	100%
4 I had no worries or concerns	104	
Missing responses	112	

Answered by all

D5 Were you able to speak to a doctor about your baby as much as you wanted?

	Number	Percentage
1 Yes, always or nearly always	3133	36%
2 Yes, to some extent	4034	46%
3 No	1657	19%
Total specific responses	8824	100%
4 I did not want or need to speak to a doctor	305	
Missing responses	107	

Answered by all

D6 Were the nurses on the unit sensitive to your emotions and feelings?

	Number	Percentage
1 Yes, always or nearly always	6656	73%
2 Yes, sometimes	2060	23%
3 No	397	4%
Total specific responses	9113	100%
Missing responses	123	

Answered by all

D7 Were the doctors on the unit sensitive to your emotions and feelings?

	Number	Percentage
1 Yes, always or nearly always	5312	63%
2 Yes, sometimes	2594	31%
3 No	508	6%
Total specific responses	8414	100%
4 I had no contact with doctors on the unit	701	
Missing responses	121	

Answered by all

D8 In your opinion, was important information about your baby passed on from one member of staff to another?

	Number	Percentage
1 Yes, always or nearly always	6419	71%
2 Yes, sometimes	2169	24%
3 No, information was not passed on	484	5%
Total specific responses	9072	100%
Missing responses	164	

Answered by all

D9 Did staff give you conflicting information about your baby's condition or care?

	Number	Percentage
1 Yes, often	1623	18%
2 Yes, sometimes	2392	26%
3 No, not at all	5028	56%
Total specific responses	9043	100%
Missing responses	193	

Answered by all

D10 As far as you know, did staff wash or clean their hands before touching your baby?

	Number	Percentage
1 Yes, always or nearly always	7732	93%
2 Yes, to some extent	525	6%
3 No	74	1%
Total specific responses	8331	100%
4 Don't know / Can't remember	805	
Missing responses	100	

Answered by all

D11 Did staff refer to your baby by his/her first name?

	Number	Percentage
1 Yes, always or nearly always	7251	85%
2 Yes, to some extent	980	11%
3 No	302	3%
Total specific responses	8533	100%
4 My baby did not have a name	577	
Missing responses	126	

Answered by all

D12 Overall, did staff treat you with respect and courtesy?

	Number	Percentage
1 Yes, always or nearly always	7823	86%
2 Yes, sometimes	1133	12%
3 No	159	2%
Total specific responses	9115	100%
Missing responses	121	

Answered by all

D13 Overall, did you have confidence and trust in the staff caring for your baby?

	Number	Percentage
1 Yes, always or nearly always	7796	86%
2 Yes, sometimes	1105	12%
3 No	206	2%
Total specific responses	9107	100%
Missing responses	129	

Answered by all

Your involvement in your baby's care

E1 Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?

	Number	Percentage
1 Yes, definitely	7387	81%
2 Yes, to some extent	1254	14%
3 No, I was not involved as much as I wanted	457	5%
Total specific responses	9098	100%
4 No, my baby was too ill	61	
Missing responses	77	

Answered by all

E2 Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?

	Number	Percentage
1 Yes, definitely	6788	77%
2 Yes, to some extent	1588	18%
3 No, they were not involved as much as they wanted to be	500	6%
Total specific responses	8876	100%
4 No, my baby was too ill	70	
5 I do not/did not have a partner	210	
Missing responses	80	

Answered by all

E3 Were you encouraged to touch, hold and comfort your baby?

	Number	Percentage
1 Yes, definitely	7047	77%
2 Yes, to some extent	1667	19%
3 No	448	5%
Total specific responses	9162	100%
Missing responses	74	

Answered by all

E4 Did you have as much 'kangaroo care' (skin-to-skin contact) with your baby as you wanted?

	Number	Percentage
1 Yes, definitely	4011	50%
2 Yes, to some extent	1690	21%
3 No, not as much kangaroo care as wanted	1515	19%
5 I did not know about kangaroo care	837	11%
Total specific responses	8053	100%
4 No, but this was not possible for medical reasons	1041	
Missing responses	142	

Answered by all

E5 Did the doctors and nurses include you in discussions about your baby's care and treatment?

	Number	Percentage
1 Yes, always	4996	55%
2 Yes, sometimes	3250	36%
3 No	919	10%
Total specific responses	9165	100%
Missing responses	71	

Answered by all

E6 Were you told about any changes in your baby's condition or care?

	Number	Percentage
1 Yes, always or nearly always	6997	78%
2 Yes, to some extent	1727	19%
3 No, I was not told about changes	327	4%
Total specific responses	9051	100%
4 Not sure / Can't remember	115	
Missing responses	70	

Answered by all

E7 When a ward round was taking place, were you allowed to be present when your baby was being discussed?

	Number	Percentage
1 Yes, always or nearly always	4953	63%
2 Yes, to some extent	1390	18%
3 No, I was not allowed to be there	1505	19%
Total specific responses	7848	100%
4 Not sure / Don't know	1260	
Missing responses	128	

Answered by all

E8 Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?

	Number	Percentage
1 Yes, always or nearly always	4899	55%
2 Yes, sometimes	2106	24%
3 No	1842	21%
Total specific responses	8847	100%
Missing responses	389	

Answered by all

E9 Overall, did staff help you feel confident in caring for your baby?

	Number	Percentage
1 Yes, definitely	6992	77%
2 Yes, to some extent	1758	19%
3 No	370	4%
Total specific responses	9120	100%
Missing responses	116	

Answered by all

E10 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?

	Number	Percentage
1 Yes, definitely	5390	76%
2 Yes, to some extent	1223	17%
3 No	482	7%
Total specific responses	7095	100%
4 I did not want to express milk	1567	
5 I could not express milk	377	
Missing responses	197	

Answered by all

E11 Were you given the equipment you needed, such as a breast pump and sterilisation equipment?

	Number	Percentage
1 Yes, definitely	5982	85%
2 Yes, to some extent	611	8%
3 No	495	7%
Total specific responses	7088	100%
Missing responses	42	

Answered by those who could express breast milk

E12 Were you given enough privacy for expressing milk for your baby?

	Number	Percentage
1 Yes, definitely	5344	77%
2 Yes, to some extent	1133	16%
3 No, and it bothered me	304	4%
4 No, but I did not mind	171	3%
Total specific responses	6952	100%
Missing responses	171	

Answered by those who could express breast milk

E13 Were there facilities on the neonatal unit for the storage of breast milk?

	Number	Percentage
1 Yes	6998	99%
2 No	74	1%
Total specific responses	7072	100%
3 Don't know / Can't remember	1247	
Missing responses	393	

Answered by all

E14 If you wanted to breastfeed your baby were you given enough support to do this from neonatal staff?

	Number	Percentage
1 Yes, definitely	5095	74%
2 Yes, to some extent	1282	19%
3 No	511	8%
Total specific responses	6888	100%
4 I did not want to breastfeed my baby	1207	
5 My baby was unable to breastfeed for medical reasons	383	
Missing responses	261	

Answered by those who could express breast milk

E15 Were you given enough privacy for breast feeding your baby?

	Number	Percentage
1 Yes, definitely	4540	67%
2 Yes, to some extent	1507	22%
3 No, and it bothered me	431	6%
4 No, but I did not mind	329	5%
Total specific responses	6807	100%
Missing responses	109	

Answered by those who could breast feed their baby

E16 If you bottle fed your baby (formula milk) were you given enough support to do this from neonatal staff?

	Number	Percentage
1 Yes, definitely	4028	74%
2 Yes, to some extent	1105	20%
3 No	282	5%
Total specific responses	5415	100%
4 I did not want to bottle feed my baby	2199	
5 My baby was unable to bottle feed for medical reasons	269	
Missing responses	1353	

Answered by all

Environment and facilities

F1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?

	Number	Percentage
1 Yes, always or nearly always	5703	63%
2 Yes, to some extent	2128	23%
3 No	650	7%
4 No, but I did not mind	641	7%
Total specific responses	9122	100%
Missing responses	114	

Answered by all

F2. Thinking about the environment of the unit which, if any, of the following could have been improved?

	Number	% (Base: Respondents)	% (Base: Responses)
F2_1 Noise levels	1053	12%	10%
F2_2 Light levels	827	9%	8%
F2_3 Temperature	1378	15%	13%
F2_4 Cleanliness	418	5%	4%
F2_5 Baby's comfort (eg baby nests, gel pads)	713	8%	7%
F2_6 Other	708	8%	7%
F2_7 No improvements were needed	5497	63%	52%
Total	8759	120%	100%
1 Missing responses	477		

Answered by all

F3 Was there enough space for you to sit alongside your baby's cot in the unit?

	Number	Percentage
1 Yes, always or nearly always	5944	66%
2 Yes, sometimes	2833	31%
3 No, never	308	3%
Total specific responses	9085	100%
Missing responses	151	

Answered by all

F4 In your opinion, was there adequate security on the neonatal unit?

	Number	Percentage
1 Yes, definitely	6995	77%
2 Yes, to some extent	1759	19%
3 No	373	4%
Total specific responses	9127	100%
Missing responses	109	

Answered by all

F5 If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?

	Number	Percentage
1 Yes, always or nearly always	3102	44%
2 Yes, sometimes	1181	17%
3 No	2743	39%
Total specific responses	7026	100%
4 I did not want/need to stay overnight	1835	
Missing responses	375	

Answered by all

F6 Were you able to visit your baby on the unit as much as you wanted to?

	Number	Percentage
1 Yes, definitely	8050	89%
2 Yes, to some extent	742	8%
3 No	215	2%
Total specific responses	9007	100%
4 I did not visit my baby	66	
Missing responses	163	

Answered by all

F7. If you were not able to visit your baby as much as you wanted, what was the reason(s) for this?

	Number	% (Base: Respondents)	% (Base: Responses)
F7_1 My baby was at a different hospital	18	2%	1%
F7_2 I was not well enough to visit my baby	300	39%	30%
F7_3 The unit was a long way from home	95	12%	10%
F7_4 I needed to care for my other children	189	25%	19%
F7_5 It was expensive to travel to the unit	72	9%	7%
F7_6 Other	347	43%	33%
Total	786	130%	100%
1 Missing responses	189		

Answered by those who were not able to visit their baby as much as they wanted

F8 If you had your other children with you when visiting the unit, was there somewhere they could play?

	Number	Percentage
2 Yes, there was a supervised play room/area	322	9%
3 Yes, there was an unsupervised play room/area	1816	49%
4 No, there was nowhere for them to play	1201	32%
5 Children were not allowed to visit the unit	376	10%
Total specific responses	3715	100%
1 I do not have any other children	4723	
Missing responses	798	

Answered by all

**F9 Were you able to contact the unit by telephone
whenever you needed to?**

	Number	Percentage
1 Yes, always or nearly always	6083	92%
2 Yes, sometimes	396	6%
3 No, never	144	2%
Total specific responses	6623	100%
4 I did not contact the unit by telephone	2328	
Missing responses	285	

Answered by all

Information and support for parents

**G1 Were you given enough written information to help
you understand your baby's condition and
treatment?**

	Number	Percentage
1 Yes, definitely	3299	40%
2 Yes, to some extent	1742	22%
3 No, I was not given enough written information	967	12%
4 I did not get any written information	2264	27%
Total specific responses	8272	100%
5 I did not want or need any written information	820	
Missing responses	144	

Answered by all

G2 If you needed help understanding written or spoken English, was information given in a language you could understand?

	Number	Percentage
1 Yes	714	78%
2 No	197	22%
Total specific responses	911	100%
3 I do not need help understanding English	7993	
Missing responses	332	

Answered by all

G3 When you asked questions about your baby's condition and treatment, did you get answers you could understand?

	Number	Percentage
1 Yes, always or nearly always	6639	73%
2 Yes, sometimes	2222	25%
3 No	259	3%
Total specific responses	9120	100%
4 I did not ask any questions	53	
Missing responses	63	

Answered by all

G4 Did a member of staff explain the purpose of any tests your baby had in a way you could understand?

	Number	Percentage
1 Yes, always or nearly always	7159	79%
2 Yes, sometimes	1657	18%
3 No	242	3%
Total specific responses	9058	100%
4 My baby did not have any tests	105	
Missing responses	73	

Answered by all

G5 If your baby had any surgery, did a member of staff explain the operation and its outcome in a way you could understand?

	Number	Percentage
1 Yes, always or nearly always	562	77%
2 Yes, sometimes	98	14%
3 No	68	9%
Total specific responses	728	100%
4 My baby did not have any surgery	8220	
Missing responses	288	

Answered by all

G6 Did you read your baby's medical notes (not just the nursing notes) while they were in the neonatal unit?

	Number	Percentage
1 Yes	4005	44%
2 No, but I wanted to read them	1809	20%
3 No, but I did not want to read them	757	8%
4 I did not know about or see the medical notes	2519	27%
Total specific responses	9090	100%
Missing responses	146	

Answered by all

G7 Were you offered emotional support or counselling services?

	Number	Percentage
1 Yes	1653	18%
2 No, but I would have liked to have been offered this	2295	25%
3 I did not need any emotional support or counselling	5128	56%
Total specific responses	9076	100%
Missing responses	160	

Answered by all

G8 Were you given information about any help you could get with travelling expenses, parking costs or food vouchers?

	Number	Percentage
1 Yes, definitely	1845	25%
2 Yes, to some extent	1656	22%
3 No	3919	53%
Total specific responses	7420	100%
4 I did not want/need this information	1684	
Missing responses	132	

Answered by all

G9 Did staff give you any information about parent support groups, such as Bliss or other local groups?

	Number	Percentage
1 Yes, staff gave me this information	2524	32%
2 No, but this information was available in the unit (e.g. a leaflet in the parents' room)	2748	35%
3 No, I did not get this information	2697	34%
Total specific responses	7969	100%
4 Don't know / Can't remember	1118	
Missing responses	149	

Answered by all

Discharge from the neonatal unit

H1 In total, how long did your baby stay in neonatal care (include all the hospitals they stayed in)?

	Number	Percentage
1 Up to one week	4291	47%
2 More than 1 week but less than 4 weeks	3252	36%
3 More than 4 weeks but less than 8 weeks	918	10%
4 More than 8 weeks but less than 12 weeks	372	4%
5 More than 12 weeks	252	3%
Total specific responses	9085	100%
Missing responses	151	

Answered by all

H2 In your opinion, was your baby's stay in neonatal care?

	Number	Percentage
1 Shorter than was needed	446	5%
2 About right	7901	86%
3 Longer than was needed	779	9%
Total specific responses	9126	100%
Missing responses	110	

Answered by all

H3 When your baby was discharged from the neonatal unit, where did they go next?

	Number	Percentage
1 A hospital maternity ward	2634	29%
2 Another ward in the hospital	358	4%
3 Home	6090	67%
4 Somewhere else	76	1%
Total specific responses	9158	100%
Missing responses	78	

Answered by all

H4 Were you offered accommodation overnight at the hospital before your baby came home?

	Number	Percentage
1 Yes	4827	80%
2 No, but I would have liked it	238	4%
3 No, but I did not want or need it	970	16%
Total specific responses	6035	100%
Missing responses	87	

Answered by all

H5 Did you feel prepared for your baby's discharge from neonatal care?

	Number	Percentage
1 Yes, definitely	6816	75%
2 Yes, to some extent	1986	22%
3 No	356	4%
Total specific responses	9158	100%
Missing responses	78	

Answered by all

H6 Did your baby need any special equipment when s/he was discharged from the unit?

	Number	Percentage
1 Yes	860	9%
2 No	8310	91%
Total specific responses	9170	100%
Missing responses	66	

Answered by all

H7 Were you given enough information and guidance on using the equipment when your baby left the neonatal unit?

	Number	Percentage
1 Yes, definitely	677	78%
2 Yes, to some extent	139	17%
3 No	47	5%
Total specific responses	863	100%
Missing responses	8	

Answered by those whose baby needed special equipment when they were discharged home

H8 Were you given enough information on what to expect in terms of your baby's progress and recovery?

	Number	Percentage
1 Yes, definitely	4912	54%
2 Yes, to some extent	2854	32%
3 No	1334	15%
Total specific responses	9100	100%
Missing responses	136	

Answered by all

H9. After your baby arrived home, did you have contact with neonatal staff?

	Number	% (Base: Respondents)	% (Base: Responses)
H9_1 Yes, by telephone	2055	23%	19%
H9_2 Yes, staff from the unit visited me at home	1659	18%	15%
H9_3 Yes, my baby had a follow up hospital appointment	2711	30%	24%
H9_4 No, but I would have liked contact with neonatal staff	969	11%	9%
H9_5 No, I did not want/need contact with neonatal staff	3798	41%	34%
Total	9156	122%	100%
1 Missing responses	80		

Answered by all

H10. After your baby arrived home, which of the following health professionals did you see?

	Number	% (Base: Respondents)	% (Base: Responses)
H10_1 Health visitor	8813	96%	43%
H10_2 Midwife	6704	73%	32%
H10_3 Neonatal nurse	1588	17%	8%
H10_4 GP	2811	31%	14%
H10_5 Other professional	769	9%	4%
H10_6 None	48	1%	0%
Total	9192	225%	100%
1 Missing responses	44		

Answered by all

H11 If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?

	Number	Percentage
1 Yes, definitely	3444	39%
2 Yes, to some extent	3072	35%
3 No	2340	26%
Total specific responses	8856	100%
4 I did not see a health visitor	133	
Missing responses	0	

Answered by those who had seen a health professional

H12 Overall, after your baby arrived home, did you get enough support from health professionals?

	Number	Percentage
1 Yes, definitely	5324	58%
2 Yes, to some extent	2880	32%
3 No	888	10%
Total specific responses	9092	100%
Missing responses	0	

Answered by those who had seen a health professional

Care in another hospital

J1 Did your baby stay in a neonatal unit in more than one hospital?

	Number	Percentage
1 Yes	1126	13%
2 No	7798	87%
Total specific responses	8924	100%
Missing responses	312	

Answered by all

J2 Did your baby spend most of its time in the neonatal unit s/he was discharged from (ie the last unit they stayed in)?

	Number	Percentage
1 Yes, my baby spent most time in the unit s/he was discharged from	701	63%
2 No, my baby spent most of its time in another unit	289	26%
3 My baby stayed the same amount of time in two or more different units	123	11%
Total specific responses	1113	100%
Missing responses	24	

Answered by those whose baby stayed in more than one neonatal unit

J4 Did staff keep you up to date with your baby's condition and progress?

	Number	Percentage
1 Yes, always or nearly always	267	85%
2 Yes, sometimes	48	14%
3 No	6	2%
Total specific responses	321	100%
Missing responses	3	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J5 Were you able to speak to a doctor about your baby as much as you wanted?

	Number	Percentage
1 Yes, always or nearly always	189	61%
2 Yes, to some extent	85	28%
3 No	40	12%
Total specific responses	314	100%
4 I did not want or need to speak to a doctor	4	
Missing responses	4	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J6 Were the nurses on the unit sensitive to your emotions and feelings?

	Number	Percentage
1 Yes, always or nearly always	240	74%
2 Yes, sometimes	74	24%
3 No	9	3%
Total specific responses	323	100%
Missing responses	4	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J7 Were the doctors on the unit sensitive to your emotions and feelings?

	Number	Percentage
1 Yes, always or nearly always	221	72%
2 Yes, sometimes	74	25%
3 No	14	4%
Total specific responses	309	100%
4 I had no contact with doctors on the unit	12	
Missing responses	5	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J8 Overall, did staff treat you with respect and courtesy?

	Number	Percentage
1 Yes, always or nearly always	276	86%
2 Yes, sometimes	35	11%
3 No	10	2%
Total specific responses	321	100%
Missing responses	5	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

**J9 Overall, did staff help you feel confident in caring
for your baby?**

	Number	Percentage
1 Yes, always or nearly always	276	86%
2 Yes, sometimes	36	12%
3 No	9	3%
Total specific responses	321	100%
Missing responses	4	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

**J10 Were you involved as much as you wanted in the
day-to-day care of your baby, such as nappy
changing and feeding?**

	Number	Percentage
1 Yes, definitely	233	77%
2 Yes, to some extent	56	18%
3 No, I was not involved as much as I wanted	17	5%
Total specific responses	306	100%
4 No, my baby was too ill	14	
Missing responses	6	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J11 Did you have as much kangaroo care (skin to skin contact) with your baby as you wanted?

	Number	Percentage
1 Yes, definitely	132	54%
2 Yes, to some extent	52	20%
3 No, not as much kangaroo care as wanted	43	16%
5 I did not know about kangaroo care	23	10%
Total specific responses	250	100%
4 No, but this was not possible for medical reasons	68	
Missing responses	8	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J12 Overall, did staff help you feel confident in caring for your baby?

	Number	Percentage
1 Yes, definitely	252	77%
2 Yes, to some extent	64	21%
3 No	6	2%
Total specific responses	322	100%
Missing responses	6	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J13 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?

	Number	Percentage
1 Yes, definitely	224	79%
2 Yes, to some extent	42	16%
3 No	18	6%
Total specific responses	284	100%
4 I did not want to express milk	26	
5 I could not express milk	14	
Missing responses	5	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J14 If you wanted to breastfeed your baby were you given enough support to do this from neonatal staff?

	Number	Percentage
1 Yes, definitely	152	70%
2 Yes, to some extent	41	19%
3 No	21	12%
Total specific responses	214	100%
4 I did not want to breastfeed my baby	39	
5 My baby was unable to breastfeed for medical reasons	66	
Missing responses	8	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J15 If you bottle fed your baby (formula milk) were you given enough support to do this from neonatal staff?

	Number	Percentage
1 Yes, definitely	111	73%
2 Yes, to some extent	37	21%
3 No	10	6%
Total specific responses	158	100%
4 I did not want to bottle feed my baby	73	
5 My baby was unable to bottle feed for medical reasons	65	
Missing responses	28	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

J16 Were you offered emotional support or counselling?

	Number	Percentage
1 Yes	119	40%
2 No, but I would have liked to have been offered this	102	32%
3 I did not need any emotional support or counselling	98	29%
Total specific responses	319	100%
Missing responses	10	

Answered by those whose baby stayed in another unit for most of its time in neonatal care

You and your baby

K1 Did you give birth to a single baby, twins or more in your most recent pregnancy?

	Number	Percentage
1 A single baby	8416	90%
2 Twins	914	10%
3 Triplets, quads or more	29	0%
Total specific responses	9359	100%
Missing responses	83	

Answered by all

K2 Roughly how many weeks pregnant were you when your baby was born?

	Number	Percentage
1 Before I was 25 weeks pregnant	69	1%
2 When I was 25 to 29 weeks pregnant	643	7%
3 When I was 30 to 32 weeks pregnant	1130	12%
4 When I was 33 to 37 weeks pregnant	3772	40%
5 When I was 38 weeks pregnant or more	3719	40%
Total specific responses	9333	100%
Missing responses	109	

Answered by all

K3 How much did your baby weigh at birth?

	Number	Percentage
1 Less than 1000g (1kg / 2lb 3oz)	372	4%
2 1000g to 1500g (1kg to 1.5.kg / 2lb 3oz to 3lb 5oz)	879	9%
3 1500g to 2500g (1.5kg to 2.5kg / 3lb 5oz to 5lb 8oz)	3099	33%
4 More than 2500g (2.5kg / 5lb 8oz)	4952	53%
Total specific responses	9302	100%
Missing responses	140	

Answered by all

K4 How many babies have you given birth to before this pregnancy?

	Number	Percentage
1 None	5365	57%
2 1-2	3412	36%
3 3 or more	610	6%
Total specific responses	9387	100%
Missing responses	55	

Answered by all

K5 Have you previously had a baby admitted to a neonatal unit?

	Number	Percentage
1 Yes	963	24%
2 No	3061	76%
Total specific responses	4024	100%
Missing responses	18	

Answered by those who had previously given birth to a baby

K6 Who filled in this questionnaire?

	Number	Percentage
1 The baby's mother	7604	82%
2 The baby's father	308	3%
3 Parents together	1342	14%
4 The baby's guardian(s)	11	0%
Total specific responses	9265	100%
Missing responses	177	

Answered by all

**K7 To which of these ethnic groups would you say
you belong?**

	Number	Percentage
1 White	7906	84%
2 Mixed	151	2%
3 Asian or Asian British	793	8%
4 Black or Black British	354	4%
5 Chinese or Other Ethnic Group	235	2%
Total specific responses	9439	100%
999 Missing	3	

Answered by all

**K8 Do you have a long-standing physical or mental
health problem or disability?**

	Number	Percentage
1 Yes	486	5%
2 No	8791	94%
3 I'd rather not say	108	1%
Total specific responses	9385	100%
Missing responses	57	

Answered by all

K9 Does this problem or disability affect your day-to-day activities?

	Number	Percentage
1 Yes, definitely	125	26%
2 Yes, to some extent	190	39%
3 No	167	35%
Total specific responses	482	100%
Missing responses	8	

Answered by those who have a long-standing physical or mental health problem or disability

Mother's age group from response or sample if missing

	Number	Percentage
1 16-27	2141	23%
2 28-31	2153	23%
3 32-35	2319	25%
4 36 and over	2732	29%
Total specific responses	9345	100%
Missingdata	97	

Answered by all

Appendix 6: Results by different groups of respondents

Mean scores

It was important to examine the extent to which parents' experiences of neonatal care were influenced by their demographic characteristics, the 'health status' of their baby, and the type of unit that their baby was discharged from. To undertake this analysis, question response options were scored using a scale of 0 to 100. A response option that was assigned a score of 100 reflects the most positive parent experience, while a score of 0 indicates the worst experience. An overall score was calculated for each respondent by taking a mean of the scores to each rated question. Higher mean scores indicated a more positive parent experience.

This analysis showed that older parents tend to report more positive experiences than younger respondents, as do parents of babies born at a later gestational age (and/or babies of greater birth weight and/or babies that had shorter stay in neonatal care). For the unit-level comparison of results (i.e. unit-level benchmark reporting), the data was standardised by the age of respondents and by the gestational age of their baby at birth. This was to ensure that no unit appeared better or worse than another because of its respondent profile allowing a more accurate comparison of results.

Demographic characteristics

Maternal age

An analysis of variance (table 1) showed that the overall mean score was significantly higher for those mothers in the older age groups, suggesting that older respondents tend to report more positive experiences of neonatal services than younger respondents ($f=2.2$, $df=4$, $p=0.62$). This finding corresponds with the results of an analysis based on the national surveys of patients, which showed that older patients generally gave higher scores (i.e. answer more favourably about their experience) than younger patients (ref).

Table 1 Mean scores by maternal age group

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Aged 16-27 years	2141	74	16.33	73.19	74.58
Aged 28-31 years	2153	77	14.63	76.21	77.44
Aged 32-35 years	2319	78	14.21	77.41	78.56
Aged 36 years and over	2732	79	14.22	78.11	79.18
Total	9345	77	14.93	76.67	77.27

($f=46.2$, $df=3$, $p>0.001$)

Ethnic group

Although there were some differences in the overall mean score by the respondent's ethnic group, these were not statistically significant at the 0.001 level (table 2), implying that ethnicity does not have a strong influence on how parents' report their experiences of neonatal care. Due to small numbers of respondents for some ethnic groups, the data were also analysed by combining all non-white ethnic groups and comparing the overall mean score for this group to the mean score for white respondents (table 3). There was not a significant difference between the two groups with the overall mean score being 77 for both.

Table 2 Mean scores by respondent ethnic group

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
White	7906	77	14.97	76.68	77.34
Mixed	151	73	16.15	70.72	75.92
Black or Black British	793	76	14.85	75.29	77.36
Asian or Asian British	354	78	13.28	76.72	79.49
Chinese or other ethnic group	235	78	14.00	76.49	80.09
Total	9439	77	14.91	76.66	77.26

($f=3.6$, $df=4$, $p=0.006$)

Table 3 Mean scores by white and non-white ethnic groups

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
White	7906	77	14.97	76.68	77.34
Non-white	1533	77	14.56	76.01	77.47
Total	9439	77	14.91	76.66	77.26

($f=0.4$, $df=1$, $p=0.526$)

Baby's health status

Questions K2- 'Roughly how many weeks pregnant were you when your baby was born?', K3 'How much did your baby weight at birth?' and H1 'In total, how long did your baby stay in neonatal care?' can be used as proxies for the baby's health status as it could be assumed that those babies born at any earlier gestational age, and/or those babies born of lower weight and/or babies that stayed in neonatal care for a longer period of time had more complex health needs requiring a greater level of neonatal care.

Table 4 shows the overall mean score was higher for parents of babies who were born at any earlier gestation (78), than those parents of babies born at 38 weeks or more (76). This difference in the overall mean rating was significant ($f=39.7$, $df=1$, $p<0.001$). The overall mean score was also significantly higher for those parents of babies born with a lower birth weight (Table 5) and for those parents of babies who had a longer length of stay in neonatal care (Table 6). These findings suggest that parents of babies with

greater or more complex health needs report a more positive experience of neonatal care overall.

Table 4 Mean scores by baby's gestational age at birth

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
37 weeks or less	5614	78	14.15	77.42	78.16
38 weeks or more	3719	76	15.84	75.30	76.32
Total	9333	77	14.88	76.70	77.30

($f=39.7$, $df=1$, $p>0.001$)

Table 5 Mean scores by baby's weight at birth

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Less than 1000g	372	80	13.39	79.05	81.78
1000g to 1500g	879	79	13.04	77.96	79.68
1500g to 2500g	3099	78	14.00	77.50	78.49
More than 2500g	4952	76	15.76	75.25	76.13
Total	9302	77	14.92	76.64	77.25

($f=28.4$, $df=3$, $p>0.001$)

Table 6 Mean scores by baby's length of stay in the neonatal unit

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Up to 1 week	4395	75	16.10	74.88	75.84
More than 1 week	4874	79	13.51	78.13	78.89
Total	9269	77	14.88	76.71	77.32

($f=104.8$, $df=1$, $p>0.001$)

Type of neonatal unit

The overall mean score was compared between the three different types of neonatal unit: Special Care Baby Units, Local Neonatal Units and Neonatal Intensive Care Units (Table 7). This analysis showed that the overall mean score did not differ significantly suggesting that the unit type does not have a strong influence on parents' reported experiences of the neonatal care and treatment their baby received.

Table 7 Mean scores by the type of neonatal unit

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Special Care Baby Unit	2327	77	14.77	76.75	77.95

Local Neonatal Unit	4241	77	14.85	76.40	77.30
Neonatal Intensive Care Unit	2874	77	15.13	76.25	77.36
Total	9442	77	14.92	76.66	77.26

(f=1.1, df=2, p=0.337)

Survey questions by groups of respondents

Table 8 shows the percentage of parents that responded to each response option for each survey question, broken down by the baby's gestation, the baby's birth weight and their length of time in neonatal care. Table 9 shows the results broken down by the type of unit that a baby was discharged from, parental age and ethnicity. Pearson's chi-square tests were used to determine if any differences in the proportions of respondents by these sub groups were statistically significant. However, further analysis is required to unpick this data in detail.

Table 8: A breakdown of results by different groups of respondents (Baby characteristics)

*The Chi-square statistic is significant at the 0.05 level

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
A1 Before your baby was born, did you know that they might need care in a neonatal unit?	1 Yes	46.4%	11.2%	1262	1	.000*	59.4%	56.5%	46.5%	17.1%	1163	3	.000*	18.6%	44.9%	727	1	.000*
	2 No	53.6%	88.8%				40.6%	43.5%	53.5%	82.9%				81.4%	55.1%			
A2 Before your baby was born, were you given the chance to visit the neonatal unit?	1 Yes	41.6%	32.3%	16	2	.000*	47.8%	50.0%	41.6%	31.0%	57	6	.000*	31.2%	43.7%	50	2	.000*
	2 No, but I did not mind	36.8%	46.4%				31.8%	30.7%	35.9%	47.3%				48.6%	34.3%			
	3 No, but I would have liked this	21.6%	21.2%				20.4%	19.3%	22.5%	21.8%				20.3%	22.0%			
A3 Before your baby was born, did a member of staff from the neonatal unit talk to you about what to expect after the birth?	1 Yes, definitely	36.8%	26.8%	26	2	.000*	62.3%	44.7%	34.7%	23.4%	189	6	.000*	23.7%	39.8%	99	2	.000*
	2 Yes, to some extent	21.6%	17.7%				15.9%	28.2%	20.5%	19.1%				17.9%	22.1%			
	3 No	41.6%	55.5%				21.7%	27.1%	44.8%	57.5%				58.4%	38.1%			
B2 After the birth, were you able to touch your baby before s/he was taken to the neonatal unit?	1 Yes	80.5%	92.3%	212	1	.000*	35.3%	55.1%	84.3%	92.0%	905	3	.000*	93.1%	77.3%	381	1	.000*
	2 No	19.5%	7.7%				64.7%	44.9%	15.7%	8.0%				6.9%	22.7%			
B3 Were you given a photograph of your baby?	1 Yes	52.8%	35.7%	283	2	.000*	69.7%	62.8%	51.6%	37.7%	380	6	.000*	34.5%	56.4%	474	2	.000*
	2 No, but I would have liked this	22.2%	24.5%				14.6%	19.7%	23.0%	24.4%				25.0%	21.3%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less 25.0%	38 weeks or more 39.7%	Chi-Square	df	Sig.	Less than 1000g 15.7%	1000g to 1500g 17.5%	1500g to 2500g 25.4%	More than 2500g 37.8%	Chi-Square	df	Sig.	Up to 1 week 40.5%	More than 1 week 22.3%	Chi-Square	df	Sig.
	3 No, but I took a photograph myself																	
B4 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?	1 Yes, and this bothered me	33.4%	31.2%	40	2	.000*	33.1%	34.8%	32.3%	32.5%	84	6	.000*	29.4%	35.4%	139	2	.000*
	2 Yes, but I did not mind	24.9%	31.1%				15.3%	18.5%	27.1%	30.0%				33.0%	21.8%			
	3 No, I stayed in a separate room/area	41.7%	37.7%				51.6%	46.7%	40.6%	37.5%				37.6%	42.7%			
B5 After the birth, did a member of staff come to talk to you about your baby's condition and treatment?	1 Yes	75.6%	81.6%	43	1	.000*	78.4%	73.5%	74.5%	80.8%	50	3	.000*	81.3%	75.1%	48	1	.000*
	2 No	24.4%	18.4%				21.6%	26.5%	25.5%	19.2%				18.7%	24.9%			
B6 How long did you wait before a member of staff came to talk to you about your baby's condition and treatment?	1 Less than one hour	58.5%	58.2%	5	3	16.9%	53.3%	49.7%	60.9%	58.4%	29	9	.001*	60.9%	55.6%	16	3	.001*
	2 More than one hour but less than two	21.2%	19.4%				22.9%	24.4%	20.6%	19.4%				19.5%	21.4%			
	3 More than two hours but less than four	10.5%	11.7%				10.5%	14.2%	9.6%	11.6%				10.4%	11.9%			
	4 Four hours or more	9.7%	10.7%				13.3%	11.8%	8.9%	10.5%				9.2%	11.0%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
B7 After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?	1 Yes, staff took me	63.2%	71.2%	50	2	.000*	60.4%	56.6%	64.1%	69.6%	56	6	.000*	70.2%	62.6%	45	2	.000*
	2 Yes, family took me	25.0%	19.3%				25.7%	27.4%	24.8%	20.5%				20.3%	25.2%			
	3 No	11.8%	9.5%				13.9%	16.0%	11.1%	9.9%				9.6%	12.1%			
B8 After your baby was admitted to the neonatal unit, was your partner or companion able to see your baby as soon as they wanted?	1 Yes	95.5%	95.0%	1	1	0.25	95.5%	93.8%	95.9%	95.1%	6	3	0.10	95.3%	95.3%	0	1	0.95
	2 No	4.5%	5.0%				4.5%	6.2%	4.1%	4.9%				4.7%	4.7%			
B9 After you gave birth, was a partner or family member allowed to stay with you overnight?	1 Yes	18.1%	19.1%	1	1	0.28	34.7%	23.8%	15.2%	18.1%	87	3	.000*	16.6%	19.9%	13	1	.000*
	2 No	81.9%	80.9%				65.3%	76.2%	84.8%	81.9%				83.4%	80.1%			
B10 When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?	1 Yes, definitely	67.5%	61.5%	36	2	.000*	75.1%	71.7%	66.9%	61.8%	64	6	.000*	62.6%	67.1%	26	2	.000*
	2 Yes, to some extent	25.6%	29.8%				20.8%	22.9%	26.0%	29.5%				28.6%	26.3%			
	3 No, I would have liked to have spoken to somebody earlier	6.9%	8.7%				4.1%	5.5%	7.1%	8.7%				8.8%	6.6%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
B11 When your partner or companion first visited the unit, were they able to speak to a doctor or nurse about your baby's condition as soon as they wanted?	1 Yes, definitely	68.6%	61.9%	44	2	.000*	73.2%	72.1%	68.4%	62.7%	59	6	.000*	63.0%	68.5%	35	2	.000*
	2 Yes, to some extent	25.4%	30.4%				23.2%	22.9%	25.9%	29.5%				29.3%	25.8%			
	3 No, but they would have liked to have spoken to somebody earlier	6.0%	7.7%				3.6%	5.0%	5.7%	7.9%				7.7%	5.6%			
B12 When you first visited your baby, were you given enough information about the neonatal unit?	1 Yes, definitely	59.1%	54.4%	24	2	.000*	71.8%	63.7%	57.8%	54.3%	76	6	.000*	54.9%	59.3%	23	2	.000*
	2 Yes, to some extent	26.6%	28.1%				20.9%	26.0%	26.9%	28.3%				27.9%	26.6%			
	3 No	14.3%	17.5%				7.3%	10.2%	15.4%	17.4%				17.2%	14.1%			
B13 When you first visited your baby, was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?	1 Yes, definitely	56.1%	50.4%	34	2	.000*	60.9%	56.9%	56.4%	50.9%	53	6	.000*	51.3%	56.1%	44	2	.000*
	2 Yes, to some extent	28.7%	30.5%				29.2%	30.8%	27.7%	30.4%				29.3%	29.6%			
	3 No	15.1%	19.0%				9.9%	12.3%	15.9%	18.7%				19.4%	14.3%			
B14 When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?	1 Yes, definitely	78.1%	68.0%	132	2	.000*	89.9%	83.6%	77.8%	68.5%	211	6	.000*	67.1%	80.3%	220	2	.000*
	2 Yes, to some extent	13.3%	16.7%				7.9%	12.2%	13.0%	16.9%				17.6%	12.1%			
	3 No	8.6%	15.3%				2.2%	4.1%	9.1%	14.6%				15.3%	7.5%			
C1 Was your baby ever transferred (moved) to a neonatal unit at a different hospital?	1 Yes	16.2%	6.5%	191	1	.000*	53.3%	31.9%	10.9%	6.6%	1033	3	.000*	2.4%	21.4%	763	1	.000*
	2 No, s/he stayed in the same hospital	83.8%	93.5%				46.7%	68.1%	89.1%	93.4%				97.6%	78.6%			
C2 Were you and your baby ever cared for in separate hospitals?	1 Yes	31.3%	39.8%	6	1	0.01	31.3%	30.2%	31.3%	39.0%	7	3	0.08	41.1%	32.5%	3	1	0.07
	2 No	68.7%	60.2%				68.7%	69.8%	68.7%	61.0%				58.9%	67.5%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
C3 How many different hospitals did your baby stay in?	1 Two	37 weeks or less 85.8%	38 weeks or more 91.8%	Chi-Square	df	Sig.	Less than 1000g 73.0%	1000g to 1500g 85.5%	1500g to 2500g 90.9%	More than 2500g 93.0%	Chi-Square	df	Sig.	Up to 1 week 95.7%	More than 1 week 86.2%	Chi-Square	df	Sig.
	2 Three	11.7%	7.8%	7	2	0.03	18.9%	12.7%	8.8%	6.4%	68	6	.000*	4.3%	11.5%	7	2	0.03
	3 Four or more	2.5%	.4%				8.2%	1.8%	.3%	.6%				.0%	2.3%			
C4 Did staff clearly explain to you why your baby was being transferred to a different hospital?	1 Yes, definitely	84.4%	82.8%	0	2	0.80	87.0%	83.9%	83.2%	84.1%	3	6	0.86	83.5%	84.2%	0	2	0.79
	2 Yes, to some extent	13.3%	15.0%				10.8%	13.4%	15.1%	14.0%				13.4%	13.7%			
	3 No	2.3%	2.1%				2.2%	2.7%	1.6%	1.9%				3.1%	2.0%			
C5 Did you feel you were given enough warning by staff that your baby was going to be transferred?	1 Yes, definitely	57.7%	65.5%	5	2	0.09	56.8%	58.8%	57.1%	64.7%	6	6	0.45	69.2%	58.6%	4	2	0.11
	2 Yes, to some extent	23.7%	21.6%				24.3%	23.1%	23.2%	21.9%				19.8%	23.6%			
	3 No	18.7%	12.9%				18.9%	18.1%	19.7%	13.4%				11.0%	17.8%			
C6 In your opinion, were staff in the new unit fully aware of the care your baby had received so far?	1 Yes, definitely	65.9%	74.8%	7	2	0.03	58.7%	64.3%	65.9%	77.2%	22	6	.001*	68.1%	67.7%	0	2	0.99
	2 Yes, to some extent	27.3%	19.6%				31.7%	28.1%	28.0%	17.9%				25.5%	25.6%			
	3 No	6.8%	5.7%				9.5%	7.6%	6.1%	4.9%				6.4%	6.7%			
C7 Were you given enough information about the hospital/unit where your baby was being transferred (such as location and facilities)?	1 Yes, definitely	61.7%	59.2%	5	2	0.07	55.6%	64.7%	62.0%	60.2%	10	6	0.13	65.3%	60.8%	1	2	0.53
	2 Yes, to some extent	28.1%	34.3%				34.2%	25.7%	26.8%	33.0%				28.4%	29.7%			
	3 No	10.2%	6.4%				10.2%	9.7%	11.2%	6.8%				6.3%	9.5%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less 58.9%	38 weeks or more 53.2%	Chi-Square	df	Sig.	Less than 1000g 64.7%	1000g to 1500g 64.3%	1500g to 2500g 59.3%	More than 2500g 52.6%	Chi-Square	df	Sig.	Up to 1 week 50.5%	More than 1 week 62.0%	Chi-Square	df	Sig.
D1 When you visited the unit, did the staff caring for your baby introduce themselves to you?	1 Yes, all of the staff introduced themselves			41	2	.000*					93	6	.000*			160	2	.000*
	2 Some of the staff introduced themselves	35.5%	38.5%				31.0%	31.6%	35.6%	38.8%				40.2%	33.7%			
	3 Very few or none of the staff introduced themselves	5.7%	8.3%				4.4%	4.1%	5.1%	8.5%				9.3%	4.4%			
D2 Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?	1 Yes	88.2%	82.5%	58	1	.000*	92.7%	92.9%	87.9%	82.9%	96	3	.000*	81.3%	90.4%	157	1	.000*
	2 No	11.8%	17.5%				7.3%	7.1%	12.1%	17.1%				18.7%	9.6%			
D3 Did staff keep you up to date with your baby's condition and progress?	1 Yes, always or nearly always	80.8%	75.7%	44	2	.000*	81.0%	83.1%	81.3%	76.1%	56	6	.000*	74.9%	82.5%	102	2	.000*
	2 Yes, sometimes	16.8%	20.0%				17.1%	15.7%	16.2%	19.9%				20.6%	15.8%			
	3 No	2.4%	4.3%				1.9%	1.1%	2.5%	4.0%				4.5%	1.8%			
D4 Were you able to talk to staff on the unit about your worries and concerns?	1 Yes, always or nearly always	77.7%	73.5%	28	2	.000*	76.3%	75.9%	79.3%	73.6%	59	6	.000*	73.2%	78.6%	54	2	.000*
	2 Yes, sometimes	19.9%	22.6%				22.3%	22.5%	18.8%	22.2%				22.8%	19.5%			
	3 No	2.4%	3.9%				1.4%	1.6%	1.9%	4.1%				4.0%	2.0%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
D5 Were you able to speak to a doctor about your baby as much as you wanted?	1 Yes, always or nearly always	36.6%	33.6%	17	2	.000*	49.7%	42.9%	34.3%	33.1%	92	6	.000*	32.1%	38.1%	88	2	.000*
	2 Yes, to some extent	45.8%	45.6%				39.3%	45.4%	46.6%	46.0%				45.1%	46.6%			
	3 No	17.6%	20.8%				10.9%	11.7%	19.1%	20.9%				22.8%	15.3%			
D6 Were the nurses on the unit sensitive to your emotions and feelings?	1 Yes, always or nearly always	72.9%	73.3%	3	2	0.20	71.0%	70.8%	73.9%	72.9%	16	6	0.02	73.0%	73.2%	8	2	0.01
	2 Yes, sometimes	23.0%	22.0%				25.5%	26.3%	21.7%	22.4%				22.1%	23.0%			
	3 No	4.1%	4.8%				3.5%	2.9%	4.4%	4.8%				5.0%	3.8%			
D7 Were the doctors on the unit sensitive to your emotions and feelings?	1 Yes, always or nearly always	62.8%	63.3%	3	2	0.28	66.5%	61.4%	62.9%	63.0%	15	6	0.02	62.7%	63.3%	11	2	.005*
	2 Yes, sometimes	31.4%	30.2%				28.8%	33.9%	31.6%	30.2%				30.4%	31.5%			
	3 No	5.8%	6.5%				4.7%	4.7%	5.5%	6.8%				6.9%	5.2%			
D8 In your opinion, was important information about your baby passed on from one member of staff to another?	1 Yes, always or nearly always	71.3%	69.8%	15	2	.000*	67.9%	68.8%	72.6%	70.0%	27	6	.000*	69.9%	71.8%	28	2	.000*
	2 Yes, sometimes	24.1%	23.7%				26.3%	26.8%	23.3%	23.7%				23.5%	24.0%			
	3 No, information was not passed on	4.6%	6.5%				5.8%	4.4%	4.1%	6.3%				6.6%	4.1%			
D9 Did staff give you conflicting information about your baby's condition or care?	1 Yes, often	18.9%	16.5%	37	2	.000*	26.4%	19.9%	18.5%	16.2%	88	6	.000*	15.8%	19.5%	98	2	.000*
	2 Yes, sometimes	28.1%	24.0%				32.4%	33.3%	26.7%	24.6%				22.9%	29.6%			
	3 No, not at all	53.1%	59.5%				41.2%	46.8%	54.8%	59.2%				61.2%	50.9%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
D10 As far as you know, did staff wash or clean their hands before touching your baby?	1 Yes, always or nearly always	93.4%	92.0%	14	2	.001*	88.4%	93.4%	94.0%	92.3%	24	6	.001*	92.2%	93.3%	10	2	.005*
	2 Yes, to some extent	6.0%	6.6%				10.2%	6.3%	5.3%	6.6%				6.6%	6.1%			
	3 No	.6%	1.3%				1.4%	.2%	.7%	1.1%				1.3%	.6%			
D11 Did staff refer to your baby by his/her first name?	1 Yes, always or nearly always	87.4%	81.1%	70	2	.000*	88.6%	88.0%	87.5%	82.5%	48	6	.000*	80.9%	88.7%	114	2	.000*
	2 Yes, to some extent	10.0%	13.9%				8.9%	9.4%	9.9%	13.1%				14.1%	9.2%			
	3 No	2.6%	5.0%				2.5%	2.6%	2.6%	4.4%				5.1%	2.1%			
D12 Overall, did staff treat you with respect and courtesy?	1 Yes, always or nearly always	86.0%	85.6%	2	2	0.34	86.1%	85.7%	86.3%	85.4%	10	6	0.13	85.3%	86.3%	4	2	0.16
	2 Yes, sometimes	12.5%	12.5%				11.4%	13.5%	12.2%	12.5%				12.7%	12.2%			
	3 No	1.6%	2.0%				2.5%	.8%	1.5%	2.0%				2.0%	1.5%			
D13 Overall, did you have confidence and trust in the staff caring for your baby?	1 Yes, always or nearly always	85.6%	85.7%	1	2	0.72	78.7%	82.0%	87.0%	85.9%	36	6	.000*	86.5%	84.8%	11	2	.003*
	2 Yes, sometimes	12.2%	11.9%				18.3%	16.3%	11.0%	11.6%				11.0%	13.1%			
	3 No	2.2%	2.4%				3.0%	1.7%	2.0%	2.5%				2.5%	2.0%			
E1 Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	1 Yes, definitely	82.9%	78.6%	27	2	.000*	85.1%	87.3%	84.0%	77.9%	79	6	.000*	77.0%	85.0%	113	2	.000*
	2 Yes, to some extent	12.6%	15.6%				12.4%	9.6%	11.8%	16.0%				16.0%	11.8%			
	3 No, I was not involved as much as I wanted	4.5%	5.8%				2.5%	3.1%	4.2%	6.2%				7.0%	3.2%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
E2 Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?	1 Yes, definitely	78.6%	73.3%	36	2	.000*	78.4%	82.6%	79.5%	73.2%	67	6	.000*	71.5%	80.9%	122	2	.000*
	2 Yes, to some extent	16.5%	19.9%				16.4%	14.3%	15.9%	20.0%				20.9%	15.2%			
	3 No, they were not involved as much as they wanted to be	4.9%	6.8%				5.2%	3.1%	4.6%	6.9%				7.6%	3.9%			
E3 Were you encouraged to touch, hold and comfort your baby?	1 Yes, definitely	77.0%	76.7%	1	2	0.56	81.8%	81.6%	76.9%	75.5%	32	6	.000*	76.3%	77.3%	21	2	.000*
	2 Yes, to some extent	18.3%	18.1%				15.7%	15.8%	18.5%	18.8%				17.8%	18.8%			
	3 No	4.7%	5.2%				2.4%	2.6%	4.6%	5.8%				5.9%	3.9%			
E4 Did you have as much 'kangaroo care' (skin- to-skin contact) with your baby as you wanted?	1 Yes, definitely	49.3%	50.5%	3	3	0.39	61.7%	53.0%	47.5%	49.4%	63	9	.000*	50.3%	48.8%	7	3	0.08
	2 Yes, to some extent	21.3%	20.6%				21.0%	22.8%	21.2%	20.9%				20.2%	22.1%			
	3 No, not as much kangaroo care as wanted	19.2%	18.1%				15.5%	18.0%	19.9%	18.5%				18.5%	19.2%			
	5 I did not know about kangaroo care	10.1%	10.8%				1.8%	6.1%	11.3%	11.3%				11.0%	9.9%			
E5 Did the doctors and nurses include you in discussions about your baby's care and treatment?	1 Yes, always	54.7%	54.1%	10	2	.007*	60.5%	53.5%	55.0%	53.4%	23	6	.001*	53.5%	55.1%	29	2	.000*
	2 Yes, sometimes	36.1%	34.7%				33.2%	37.8%	35.8%	35.3%				34.6%	36.4%			
	3 No	9.3%	11.2%				6.2%	8.7%	9.1%	11.3%				11.9%	8.5%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
E6 Were you told about any changes in your baby's condition or care?	1 Yes, always or nearly always	78.3%	75.7%	18	2	.000*	78.8%	78.1%	79.7%	75.2%	41	6	.000*	75.1%	79.3%	39	2	.000*
	2 Yes, to some extent	18.8%	19.7%				19.6%	19.5%	17.7%	20.2%				20.2%	18.2%			
	3 No, I was not told about changes	3.0%	4.5%				1.6%	2.4%	2.6%	4.6%				4.7%	2.5%			
E7 When a ward round was taking place, were you allowed to be present when your baby was being discussed?	1 Yes, always or nearly always	64.0%	61.4%	6	2	0.05	64.2%	63.1%	64.9%	61.6%	13	6	0.05	61.0%	64.4%	10	2	.006*
	2 Yes, to some extent	17.5%	18.2%				16.6%	19.9%	16.9%	18.0%				18.5%	17.4%			
	3 No, I was not allowed to be there	18.4%	20.4%				19.2%	17.1%	18.2%	20.4%				20.5%	18.2%			
E8 Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	1 Yes, always or nearly always	57.4%	52.4%	81	2	.000*	59.2%	58.1%	58.1%	53.0%	120	6	.000*	51.7%	58.8%	155	2	.000*
	2 Yes, sometimes	24.9%	21.9%				26.5%	28.5%	24.8%	21.9%				21.9%	25.5%			
	3 No	17.8%	25.7%				14.3%	13.4%	17.2%	25.2%				26.5%	15.8%			
E9 Overall, did staff help you feel confident in caring for your baby?	1 Yes, definitely	78.5%	73.9%	30	2	.000*	82.1%	79.7%	78.8%	74.2%	48	6	.000*	73.8%	79.2%	61	2	.000*
	2 Yes, to some extent	18.1%	21.0%				16.0%	18.6%	17.6%	20.8%				20.7%	18.1%			
	3 No	3.4%	5.1%				1.9%	1.7%	3.6%	5.0%				5.5%	2.7%			
E10 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?	1 Yes, definitely	78.3%	72.2%	64	2	.000*	80.9%	80.3%	79.5%	72.1%	84	6	.000*	70.2%	80.6%	160	2	.000*
	2 Yes, to some extent	16.7%	18.1%				16.7%	16.1%	15.4%	18.7%				19.1%	15.6%			
	3 No	5.0%	9.7%				2.4%	3.7%	5.1%	9.1%				10.7%	3.8%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
E11 Were you given the equipment you needed, such as a breast pump and sterilisation equipment?	1 Yes, definitely	87.8%	78.7%	145	2	.000*	89.8%	89.5%	87.8%	80.3%	132	6	.000*	77.1%	90.1%	297	2	.000*
	2 Yes, to some extent	7.8%	9.9%				7.5%	7.5%	8.1%	9.4%				10.4%	7.3%			
	3 No	4.3%	11.4%				2.7%	3.0%	4.1%	10.3%				12.4%	2.7%			
E12 Were you given enough privacy for expressing milk for your baby?	1 Yes, definitely	76.7%	77.0%	4	3	0.26	73.9%	77.6%	76.9%	76.7%	7	9	0.60	75.1%	78.1%	15	3	.002*
	2 Yes, to some extent	16.8%	15.6%				20.1%	16.6%	16.4%	16.0%				16.8%	16.0%			
	3 No, and it bothered me	4.1%	4.9%				4.6%	4.0%	4.3%	4.6%				5.2%	3.8%			
	4 No, but I did not mind	2.4%	2.5%				1.5%	1.8%	2.4%	2.7%				2.9%	2.1%			
E13 Were there facilities on the neonatal unit for the storage of breast milk?	1 Yes	99.4%	98.2%	20	1	.000*	99.4%	99.5%	99.4%	98.6%	13	3	.005*	98.1%	99.6%	38	1	.000*
	2 No	.6%	1.8%				.6%	.5%	.6%	1.4%				1.9%	.4%			
E14 If you wanted to breastfeed your baby were you given enough support to do this from neonatal staff?	1 Yes, definitely	74.8%	72.8%	4	2	0.15	71.4%	75.1%	76.0%	72.6%	13	6	0.05	71.5%	76.2%	38	2	.000*
	2 Yes, to some extent	18.2%	19.2%				21.4%	18.0%	17.7%	19.1%				19.1%	18.1%			
	3 No	7.0%	8.0%				7.1%	6.9%	6.4%	8.3%				9.4%	5.7%			
E15 Were you given enough privacy for breast feeding your baby?	1 Yes, definitely	67.4%	65.7%	25	3	.000*	63.5%	68.1%	68.6%	65.5%	38	9	.000*	64.1%	68.8%	63	3	.000*
	2 Yes, to some extent	22.6%	21.4%				26.2%	23.1%	22.1%	21.7%				21.8%	22.3%			
	3 No, and it bothered me	6.2%	6.5%				7.2%	5.7%	5.9%	6.6%				7.0%	5.8%			
	4 No, but I did not mind	3.8%	6.3%				3.0%	3.1%	3.4%	6.3%				7.0%	3.1%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
E16 If you bottle fed your baby (formula milk) were you given enough support to do this from neonatal staff?	1 Yes, definitely	75.3%	72.9%	10	2	.008*	76.5%	73.9%	77.0%	72.2%	26	6	.000*	71.3%	76.8%	38	2	.000*
	2 Yes, to some extent	20.1%	20.6%				20.6%	22.7%	18.4%	21.3%				21.4%	19.5%			
	3 No	4.6%	6.5%				2.8%	3.4%	4.7%	6.5%				7.3%	3.8%			
F1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?	1 Yes, always or nearly always	61.6%	64.0%	10	3	0.02	65.8%	58.4%	60.7%	63.9%	34	9	.000*	62.8%	62.2%	10	3	0.02
	2 Yes, to some extent	24.4%	21.7%				23.6%	27.5%	24.4%	21.9%				22.4%	24.2%			
	3 No	7.2%	6.9%				5.7%	9.0%	7.3%	6.8%				7.0%	7.2%			
	4 No, but I did not mind	6.8%	7.4%				4.9%	5.0%	7.6%	7.3%				7.8%	6.4%			
F3 Was there enough space for you to sit alongside your baby's cot in the unit?	1 Yes, always or nearly always	63.7%	68.0%	20	2	.000*	60.8%	59.4%	64.6%	67.4%	32	6	.000*	68.0%	63.1%	36	2	.000*
	2 Yes, sometimes	32.9%	28.6%				36.5%	37.1%	32.2%	29.0%				28.2%	33.9%			
	3 No, never	3.3%	3.4%				2.7%	3.6%	3.2%	3.5%				3.8%	3.0%			
F4 In your opinion, was there adequate security on the neonatal unit?	1 Yes, definitely	77.0%	75.8%	6	2	0.05	75.3%	73.9%	77.7%	76.4%	14	6	0.03	75.5%	77.6%	6	2	0.06
	2 Yes, to some extent	18.6%	20.5%				18.2%	22.0%	18.1%	19.8%				20.2%	18.5%			
	3 No	4.4%	3.8%				6.5%	4.1%	4.3%	3.8%				4.3%	3.9%			
F5 If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?	1 Yes, always or nearly always	40.7%	49.3%	61	2	.000*	36.2%	35.0%	40.9%	48.4%	89	6	.000*	47.8%	41.2%	103	2	.000*
	2 Yes, sometimes	18.9%	13.6%				24.7%	22.7%	18.8%	14.0%				11.9%	20.8%			
	3 No	40.4%	37.1%				39.1%	42.3%	40.2%	37.6%				40.3%	38.0%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
F6 Were you able to visit your baby on the unit as much as you wanted to?	1 Yes, definitely	90.3%	88.0%	11	2	.003*	92.1%	92.4%	90.6%	87.8%	29	6	.000*	87.1%	91.5%	47	2	.000*
	2 Yes, to some extent	7.5%	9.2%				6.5%	6.2%	7.3%	9.4%				10.0%	6.7%			
	3 No	2.2%	2.7%				1.4%	1.5%	2.1%	2.8%				2.9%	1.9%			
F8 If you had your other children with you when visiting the unit, was there somewhere they could play?	2 Yes, there was a supervised play room/area	9.1%	7.7%	24	3	.000*	12.1%	11.1%	10.1%	6.6%	68	9	.000*	6.4%	10.4%	152	3	.000*
	3 Yes, there was an unsupervised play room/area	51.3%	44.7%				59.1%	55.1%	51.5%	45.5%				40.3%	55.7%			
	4 No, there was nowhere for them to play	30.7%	35.3%				20.1%	26.9%	30.6%	35.6%				39.0%	27.1%			
	5 Children were not allowed to visit the unit	8.9%	12.3%				8.7%	6.9%	7.8%	12.3%				14.2%	6.8%			
F9 Were you able to contact the unit by telephone whenever you needed to?	1 Yes, always or nearly always	93.9%	87.5%	89	2	.000*	95.0%	95.0%	93.9%	88.7%	82	6	.000*	86.1%	94.8%	187	2	.000*
	2 Yes, sometimes	4.8%	8.5%				4.7%	4.2%	4.9%	7.7%				9.1%	4.5%			
	3 No, never	1.3%	4.0%				.3%	.8%	1.2%	3.6%				4.9%	.7%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
G1 Were you given enough written information to help you understand your baby's condition and treatment?	1 Yes, definitely	45.6%	30.3%	333	3	.000*	51.5%	50.2%	47.1%	31.5%	451	9	.000*	31.4%	46.7%	431	3	.000*
	2 Yes, to some extent	22.7%	18.6%				27.0%	23.7%	23.1%	19.0%				18.1%	23.8%			
	3 No, I was not given enough written information	10.2%	14.2%				8.5%	10.7%	10.3%	13.1%				12.9%	10.7%			
	4 I did not get any written information	21.5%	37.0%				13.0%	15.4%	19.4%	36.4%				37.7%	18.8%			
G2 If you needed help understanding written or spoken English, was information given in a language you could understand?	1 Yes	81.3%	73.4%	8	1	.005*	85.2%	82.5%	81.3%	75.2%	7	3	0.08	75.9%	80.4%	3	1	0.11
	2 No	18.7%	26.6%				14.8%	17.5%	18.7%	24.8%				24.1%	19.6%			
G3 When you asked questions about your baby's condition and treatment, did you get answers you could understand?	1 Yes, always or nearly always	74.8%	69.5%	50	2	.000*	71.5%	71.2%	76.4%	70.5%	52	6	.000*	71.4%	73.9%	28	2	.000*
	2 Yes, sometimes	23.2%	26.4%				25.7%	27.0%	21.7%	25.8%				24.8%	24.1%			
	3 No	2.0%	4.1%				2.7%	1.8%	1.8%	3.7%				3.8%	2.0%			
G4 Did a member of staff explain the purpose of any tests your baby had in a way you could understand?	1 Yes, always or nearly always	80.8%	76.2%	38	2	.000*	76.6%	76.5%	82.3%	77.4%	47	6	.000*	77.2%	80.6%	37	2	.000*
	2 Yes, sometimes	17.1%	20.2%				21.7%	21.7%	15.7%	19.2%				19.1%	17.6%			
	3 No	2.0%	3.6%				1.6%	1.7%	2.0%	3.4%				3.7%	1.8%			
G5 If your baby had any surgery, did a member of staff explain the operation and its outcome in a way you could understand?	1 Yes, always or nearly always	78.5%	74.4%	2	2	0.45	80.9%	76.2%	78.1%	75.3%	5	6	0.58	66.1%	81.0%	21	2	.000*
	2 Yes, sometimes	12.8%	15.0%				13.9%	12.3%	11.5%	15.3%				17.5%	12.2%			
	3 No	8.7%	10.6%				5.2%	11.5%	10.4%	9.5%				16.4%	6.8%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
G6 Did you read your baby's medical notes (not just the nursing notes) while they were in the neonatal unit?	1 Yes	48.3%	37.6%	140	3	.000*	48.0%	52.1%	50.6%	38.1%	267	9	.000*	37.3%	50.1%	269	3	.000*
	2 No, but I wanted to read them	19.9%	19.8%				32.2%	23.7%	17.7%	19.8%				18.3%	21.6%			
	3 No, but I did not want to read them	8.0%	8.8%				7.4%	8.0%	7.7%	8.8%				9.6%	7.2%			
	4 I did not know about or see the medical notes	23.7%	33.8%				12.5%	16.3%	24.0%	33.2%				34.9%	21.2%			
G7 Were you offered emotional support or counselling services?	1 Yes	19.7%	15.8%	29	2	.000*	39.1%	24.4%	18.0%	15.2%	199	6	.000*	13.3%	22.5%	241	2	.000*
	2 No, but I would have liked to have been offered this	25.6%	24.8%				27.9%	29.1%	25.0%	24.7%				22.0%	28.4%			
	3 I did not need any emotional support or counselling	54.6%	59.4%				33.1%	46.5%	57.0%	60.0%				64.7%	49.1%			
G8 Were you given information about any help you could get with travelling expenses, parking costs or food vouchers?	1 Yes, definitely	26.9%	21.0%	95	2	.000*	40.5%	30.6%	25.6%	21.3%	164	6	.000*	19.8%	28.4%	197	2	.000*
	2 Yes, to some extent	24.4%	18.6%				24.8%	27.0%	24.6%	19.4%				17.6%	25.5%			
	3 No	48.8%	60.5%				34.7%	42.4%	49.8%	59.2%				62.6%	46.2%			
G9 Did staff give you any information about parent	1 Yes, staff gave me this	37.9%	21.0%	397	2	.000*	54.3%	44.9%	38.9%	21.7%	601	6	.000*	19.7%	41.0%	724	2	.000*

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
support groups, such as Bliss or other local groups?	information																	
	2 No, but this information was available in the unit (e.g. a leaflet in the parents' room)	35.6%	32.6%				35.9%	39.4%	34.2%	33.7%				31.4%	37.0%			
	3 No, I did not get this information	26.5%	46.4%				9.8%	15.7%	26.9%	44.6%				48.9%	22.0%			
H1 In total, how long did your baby stay in neonatal care (include all the hospitals they stayed in)?	1 Up to one week	27.0%	78.6%	2488	4	.000*	1.6%	3.9%	25.1%	72.8%	8486	12	.000*	100.0%	.0%	9269	4	.000*
	2 More than 1 week but less than 4 weeks	46.2%	19.8%				3.5%	21.3%	60.4%	25.1%				.0%	68.0%			
	3 More than 4 weeks but less than 8 weeks	15.6%	1.5%				12.0%	46.6%	12.4%	1.8%				.0%	19.1%			
	4 More than 8 weeks but less than 12 weeks	6.6%	.1%				35.4%	21.5%	1.4%	.2%				.0%	7.7%			
	5 More than 12 weeks	4.5%	.1%				47.4%	6.8%	.6%	.1%				.0%	5.3%			
H2 In your opinion, was your baby's stay in neonatal care...	1 Shorter than was needed	6.1%	3.1%	65	2	.000*	3.3%	9.2%	6.1%	3.3%	134	6	.000*	3.9%	5.7%	24	2	.000*
	2 About right	86.6%	86.6%				91.6%	85.9%	87.3%	85.9%				86.6%	86.5%			
	3 Longer than was needed	7.4%	10.4%				5.2%	4.9%	6.6%	10.8%				9.5%	7.8%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less 17.6%	38 weeks or more 46.0%	Chi-Square	df	Sig.	Less than 1000g 2.5%	1000g to 1500g 3.1%	1500g to 2500g 15.7%	More than 2500g 43.8%	Chi-Square	df	Sig.	Up to 1 week 54.0%	More than 1 week 5.4%	Chi-Square	df	Sig.
H3 When your baby was discharged from the neonatal unit, where did they go next?	1 A hospital maternity ward			895	3	.000*					1251	9	.000*			2822	3	.000*
	2 Another ward in the hospital	3.8%	4.1%				2.5%	2.5%	4.2%	4.2%				5.1%	3.0%			
	3 Home	77.8%	49.0%				93.2%	93.1%	79.5%	51.2%				40.1%	90.7%			
	4 Somewhere else	.8%	.9%				1.9%	1.3%	.6%	.8%				.8%	.9%			
H4 Were you offered accommodation overnight at the hospital before your baby came home?	1 Yes	83.5%	71.0%	124	2	.000*	89.6%	88.4%	82.8%	72.7%	150	6	.000*	68.2%	84.5%	215	2	.000*
	2 No, but I would have liked it	3.5%	5.2%				1.7%	2.8%	3.4%	5.2%				5.0%	3.6%			
	3 No, but I did not want or need it	13.1%	23.8%				8.7%	8.7%	13.8%	22.1%				26.7%	11.9%			
H5 Did you feel prepared for your baby's discharge from neonatal care?	1 Yes, definitely	72.3%	77.7%	34	2	.000*	70.7%	67.9%	72.5%	77.2%	53	6	.000*	77.0%	72.0%	45	2	.000*
	2 Yes, to some extent	23.6%	18.8%				25.7%	28.4%	23.2%	19.2%				18.7%	24.4%			
	3 No	4.1%	3.5%				3.5%	3.7%	4.3%	3.6%				4.3%	3.6%			
H6 Did your baby need any special equipment when s/he was discharged from the unit?	1 Yes	10.8%	7.1%	36	1	.000*	30.2%	11.1%	8.6%	7.9%	206	3	.000*	8.3%	10.3%	11	1	.001*
	2 No	89.2%	92.9%				69.8%	88.9%	91.4%	92.1%				91.7%	89.7%			
H7 Were you given enough information and guidance on using the equipment when your baby left the neonatal unit?	1 Yes, definitely	81.1%	71.7%	12	2	.003*	88.5%	86.7%	80.5%	71.9%	27	6	.000*	69.1%	85.2%	35	2	.000*
	2 Yes, to some extent	13.5%	22.9%				10.6%	13.3%	14.6%	19.8%				22.0%	12.0%			
	3 No	5.4%	5.4%				.9%	.0%	4.9%	8.2%				8.9%	2.8%			

		Gestational age at birth		Pearson Chi-square Tests			Baby birth weight (grams)				Pearson Chi-square Tests			Length of stay in neonatal unit		Pearson Chi-square Tests		
		37 weeks or less	38 weeks or more	Chi-Square	df	Sig.	Less than 1000g	1000g to 1500g	1500g to 2500g	More than 2500g	Chi-Square	df	Sig.	Up to 1 week	More than 1 week	Chi-Square	df	Sig.
H8 Were you given enough information on what to expect in terms of your baby's progress and recovery?	1 Yes, definitely	52.2%	56.6%	20	2	.000*	56.0%	50.1%	52.0%	55.5%	28	6	.000*	56.3%	51.7%	24	2	.000*
	2 Yes, to some extent	33.0%	28.9%				35.0%	35.4%	32.7%	29.6%				29.1%	33.7%			
	3 No	14.8%	14.5%				9.0%	14.4%	15.2%	14.9%				14.7%	14.7%			
H11 If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?	1 Yes, definitely	40.4%	36.6%	24	2	.000*	43.4%	38.4%	41.9%	36.4%	41	6	.000*	37.7%	39.5%	17	2	.000*
	2 Yes, to some extent	34.9%	34.3%				32.5%	36.0%	34.7%	34.6%				33.6%	35.8%			
	3 No	24.7%	29.1%				24.1%	25.6%	23.4%	29.0%				28.6%	24.8%			
H12 Overall, after your baby arrived home, did you get enough support from health professionals?	1 Yes, definitely	58.0%	59.3%	4	2	0.11	62.0%	53.4%	59.1%	58.5%	18	6	.007*	59.4%	57.4%	6	2	0.04
	2 Yes, to some extent	31.7%	31.7%				28.4%	35.3%	30.4%	32.3%				31.5%	32.1%			
	3 No	10.3%	9.0%				9.6%	11.3%	10.5%	9.1%				9.1%	10.5%			
J1 Did your baby stay in a neonatal unit in more than one hospital?	1 Yes	16.8%	6.2%	220	1	.000*	53.6%	33.0%	11.2%	6.4%	1057	3	.000*	2.3%	21.8%	765	1	.000*
	2 No	83.2%	93.8%				46.4%	67.0%	88.8%	93.6%				97.7%	78.2%			

Table 9: A breakdown of results by different groups of respondents (type of unit and parent demographics)

*The Chi-square statistic is significant at the 0.05 level

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
A1 Before your baby was born, did you know that they might need care in a neonatal unit?	1 Yes	32.6%	31.3%	33.6%	5	2	0.10	33.8%	29.3%	32.7%	33.2%	12	3	.006*	32.8%	29.6%	6	1	0.01
	2 No	67.4%	68.7%	66.4%	5	2	0.10	66.2%	70.7%	67.3%	66.8%	12	3	.006*	67.2%	70.4%	6	1	0.01
A2 Before your baby was born, were you given the chance to visit the neonatal unit?	1 Yes	41.3%	40.1%	38.7%	3	4	0.61	38.3%	39.9%	40.1%	41.0%	3	6	0.85	40.2%	38.4%	1	2	0.69
	2 No, but I did not mind	38.6%	39.0%	38.0%	3	4	0.61	38.7%	39.4%	37.6%	38.9%	3	6	0.85	38.2%	40.5%	1	2	0.69
	3 No, but I would have liked this	20.1%	20.9%	23.3%	3	4	0.61	23.0%	20.7%	22.3%	20.1%	3	6	0.85	21.5%	21.1%	1	2	0.69
A3 Before your baby was born, did a member of staff from the neonatal unit talk to you about what to expect after the birth?	1 Yes, definitely	32.8%	35.5%	37.5%	5	4	0.30	35.6%	35.2%	38.4%	33.4%	9	6	0.20	34.1%	43.2%	16	2	.000*
	2 Yes, to some extent	22.9%	21.1%	19.5%	5	4	0.30	22.7%	21.9%	20.2%	19.7%	9	6	0.20	21.0%	21.2%	16	2	.000*
	3 No	44.4%	43.5%	43.0%	5	4	0.30	41.7%	42.9%	41.3%	46.9%	9	6	0.20	44.9%	35.6%	16	2	.000*
B2 After the birth, were you able to touch your baby before s/he was taken to the neonatal unit?	1 Yes	86.3%	86.6%	83.2%	15	2	.001*	82.6%	85.1%	87.6%	86.4%	20	3	.000*	86.7%	79.6%	42	1	.000*
	2 No	13.7%	13.4%	16.8%	15	2	.001*	17.4%	14.9%	12.4%	13.6%	20	3	.000*	13.3%	20.4%	42	1	.000*
B3 Were you given a photograph of your baby?	1 Yes	45.9%	44.1%	49.2%	22	4	.000*	47.3%	46.8%	45.4%	44.8%	21	6	.002*	47.3%	39.8%	62	2	.000*
	2 No, but I would have liked this	22.1%	25.0%	21.3%	22	4	.000*	25.2%	23.5%	21.9%	22.6%	21	6	.002*	21.7%	31.2%	62	2	.000*
	3 No, but I took a photograph myself	31.9%	30.9%	29.5%	22	4	.000*	27.5%	29.7%	32.7%	32.7%	21	6	.002*	31.0%	29.1%	62	2	.000*

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
B4 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?	1 Yes, and this bothered me	35.0%	33.2%	29.4%	33	4	.000*	35.8%	34.5%	31.9%	28.7%	36	6	.000*	33.7%	26.0%	43	2	.000*
	2 Yes, but I did not mind	28.1%	27.8%	26.3%	33	4	.000*	27.3%	25.9%	26.5%	29.4%	36	6	.000*	26.3%	33.4%	43	2	.000*
	3 No, I stayed in a separate room/area	36.9%	39.0%	44.3%	33	4	.000*	36.9%	39.6%	41.6%	41.9%	36	6	.000*	40.0%	40.6%	43	2	.000*
B5 After the birth, did a member of staff come to talk to you about your baby's condition and treatment?	1 Yes	80.1%	77.5%	77.2%	7	2	0.03	74.7%	77.5%	79.2%	79.8%	19	3	.000*	77.9%	78.9%	1	1	0.42
	2 No	19.9%	22.5%	22.8%	7	2	0.03	25.3%	22.5%	20.8%	20.2%	19	3	.000*	22.1%	21.1%	1	1	0.42
B6 How long did you wait before a member of staff came to talk to you about your baby's condition and treatment?	1 Less than one hour	61.6%	58.6%	55.4%	16	6	0.01	53.6%	57.4%	61.3%	60.3%	33	9	.000*	58.4%	58.3%	2	3	0.62
	2 More than one hour but less than two	19.4%	20.0%	21.7%	16	6	0.01	22.0%	21.2%	19.1%	19.6%	33	9	.000*	20.3%	21.2%	2	3	0.62
	3 More than two hours but less than four	9.5%	10.8%	12.8%	16	6	0.01	11.6%	13.0%	10.5%	9.7%	33	9	.000*	11.3%	10.0%	2	3	0.62
	4 Four hours or more	9.5%	10.5%	10.1%	16	6	0.01	12.9%	8.4%	9.1%	10.4%	33	9	.000*	10.0%	10.6%	2	3	0.62
B7 After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?	1 Yes, staff took me	71.4%	65.2%	64.3%	26	4	.000*	64.6%	65.7%	67.1%	67.7%	7	6	0.36	66.4%	66.9%	21	2	.000*
	2 Yes, family took me	19.5%	23.6%	23.8%	26	4	.000*	23.6%	22.7%	22.2%	22.4%	7	6	0.36	22.1%	25.6%	21	2	.000*
	3 No	9.1%	11.2%	11.9%	26	4	.000*	11.8%	11.6%	10.8%	9.9%	7	6	0.36	11.6%	7.6%	21	2	.000*

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
B8 After your baby was admitted to the neonatal unit, was your partner or companion able to see your baby as soon as they wanted?	1 Yes	95.6%	96.0%	93.9%	16	2	.000*	93.9%	95.1%	95.4%	96.2%	13	3	.004*	95.2%	95.7%	1	1	0.44
	2 No	4.4%	4.0%	6.1%	16	2	.000*	6.1%	4.9%	4.6%	3.8%	13	3	.004*	4.8%	4.3%	1	1	0.44
B9 After you gave birth, was a partner or family member allowed to stay with you overnight?	1 Yes	17.8%	17.3%	20.6%	10	2	.006*	18.3%	18.0%	20.0%	17.8%	4	3	0.31	18.2%	19.3%	1	1	0.40
	2 No	82.2%	82.7%	79.4%	10	2	.006*	81.7%	82.0%	80.0%	82.2%	4	3	0.31	81.8%	80.7%	1	1	0.40
B10 When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?	1 Yes, definitely	65.0%	65.5%	64.4%	1	4	0.90	61.7%	63.8%	67.3%	67.0%	31	6	.000*	64.9%	65.5%	1	2	0.58
	2 Yes, to some extent	27.3%	27.0%	27.6%	1	4	0.90	28.6%	28.5%	25.6%	26.6%	31	6	.000*	27.5%	26.4%	1	2	0.58
	3 No, I would have liked to have spoken to somebody earlier	7.7%	7.5%	7.9%	1	4	0.90	9.6%	7.7%	7.0%	6.4%	31	6	.000*	7.6%	8.1%	1	2	0.58
B11 When your partner or companion first visited the unit, were they able to speak to a doctor or nurse about your baby's condition as soon as they wanted?	1 Yes, definitely	65.8%	66.9%	64.7%	5	4	0.31	60.7%	64.4%	68.4%	69.2%	61	6	.000*	66.4%	63.6%	4	2	0.11
	2 Yes, to some extent	27.9%	26.7%	28.1%	5	4	0.31	30.1%	28.8%	25.5%	25.8%	61	6	.000*	27.0%	29.5%	4	2	0.11
	3 No, but they would have liked to have spoken to somebody earlier	6.3%	6.5%	7.3%	5	4	0.31	9.3%	6.8%	6.1%	5.0%	61	6	.000*	6.6%	6.9%	4	2	0.11
B12 When you first visited your baby, were you given enough information about the neonatal unit?	1 Yes, definitely	58.2%	57.3%	56.3%	4	4	0.36	57.7%	56.8%	57.6%	57.0%	4	6	0.64	56.8%	59.2%	3	2	0.22
	2 Yes, to some extent	27.3%	27.2%	27.0%	4	4	0.36	25.8%	27.8%	26.4%	27.9%	4	6	0.64	27.5%	25.5%	3	2	0.22
	3 No	14.5%	15.5%	16.7%	4	4	0.36	16.5%	15.4%	16.0%	15.1%	4	6	0.64	15.7%	15.4%	3	2	0.22

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
B13 When you first visited your baby, was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?	1 Yes, definitely	56.4%	54.4%	51.3%	21	4	.000*	53.1%	52.6%	54.7%	54.9%	15	6	0.02	54.4%	51.7%	7	2	0.03
	2 Yes, to some extent	29.3%	28.9%	30.0%	21	4	.000*	28.1%	31.2%	28.3%	29.8%	15	6	0.02	29.3%	29.3%	7	2	0.03
	3 No	14.3%	16.7%	18.8%	21	4	.000*	18.8%	16.3%	17.0%	15.2%	15	6	0.02	16.3%	19.0%	7	2	0.03
B14 When you first visited the unit, were infection control practices explained to you, such as hand washing and procedures for visitors?	1 Yes, definitely	74.0%	74.0%	74.1%	7	4	0.12	76.0%	74.1%	72.6%	73.3%	8	6	0.21	73.2%	78.2%	17	2	.000*
	2 Yes, to some extent	13.6%	15.3%	14.6%	7	4	0.12	13.6%	14.6%	15.9%	14.7%	8	6	0.21	15.0%	12.8%	17	2	.000*
	3 No	12.5%	10.6%	11.3%	7	4	0.12	10.5%	11.3%	11.5%	12.0%	8	6	0.21	11.7%	9.0%	17	2	.000*
C1 Was your baby ever transferred (moved) to a neonatal unit at a different hospital?	1 Yes	19.0%	9.8%	10.6%	127	2	.000*	12.6%	10.9%	13.2%	12.6%	6	3	0.14	11.7%	15.3%	15	1	.000*
	2 No, s/he stayed in the same hospital	81.0%	90.2%	89.4%	127	2	.000*	87.4%	89.1%	86.8%	87.4%	6	3	0.14	88.3%	84.7%	15	1	.000*
C2 Were you and your baby ever cared for in separate hospitals?	1 Yes	32.8%	30.8%	37.5%	4	2	0.16	26.0%	38.8%	32.3%	36.2%	11	3	0.01	29.4%	48.7%	31	1	.000*
	2 No	67.2%	69.2%	62.5%	4	2	0.16	74.0%	61.2%	67.7%	63.8%	11	3	0.01	70.6%	51.3%	31	1	.000*
C3 How many different hospitals did your baby stay in?	1 Two	86.0%	85.9%	90.0%	3	4	0.48	85.1%	85.3%	90.6%	86.2%	6	6	0.42	87.6%	84.6%	5	2	0.09
	2 Three	11.9%	11.9%	8.0%	3	4	0.48	12.6%	11.7%	8.4%	11.4%	6	6	0.42	10.7%	11.5%	5	2	0.09
	3 Four or more	2.1%	2.2%	2.0%	3	4	0.48	2.3%	3.0%	1.0%	2.4%	6	6	0.42	1.7%	4.0%	5	2	0.09
C4 Did staff clearly explain to you why your baby was being transferred to a different hospital?	1 Yes, definitely	80.4%	87.0%	84.7%	7	4	0.13	79.0%	82.1%	85.9%	86.9%	9	6	0.16	84.1%	83.1%	2	2	0.33
	2 Yes, to some extent	17.2%	10.9%	12.8%	7	4	0.13	17.3%	16.1%	12.4%	10.9%	9	6	0.16	13.9%	13.2%	2	2	0.33
	3 No	2.5%	2.1%	2.4%	7	4	0.13	3.6%	1.8%	1.8%	2.2%	9	6	0.16	2.0%	3.7%	2	2	0.33
C5 Did you feel you were given enough warning by staff that your baby was going to be transferred?	1 Yes, definitely	55.2%	59.6%	64.1%	7	4	0.16	55.7%	58.1%	57.9%	63.9%	9	6	0.15	58.6%	61.1%	0	2	0.79
	2 Yes, to some extent	24.6%	24.4%	19.6%	7	4	0.16	23.4%	22.3%	27.5%	19.0%	9	6	0.15	23.4%	22.3%	0	2	0.79
	3 No	20.1%	16.1%	16.3%	7	4	0.16	20.9%	19.5%	14.7%	17.1%	9	6	0.15	18.0%	16.6%	0	2	0.79

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
C6 In your opinion, were staff in the new unit fully aware of the care your baby had received so far?	1 Yes, definitely	69.2%	63.4%	70.7%	7	4	0.12	66.0%	70.0%	66.2%	67.9%	1	6	0.96	66.6%	71.2%	2	2	0.39
	2 Yes, to some extent	23.1%	30.2%	23.3%	7	4	0.12	27.0%	23.3%	27.4%	25.2%	1	6	0.96	26.3%	23.3%	2	2	0.39
	3 No	7.8%	6.4%	5.9%	7	4	0.12	6.9%	6.7%	6.4%	6.9%	1	6	0.96	7.1%	5.5%	2	2	0.39
C7 Were you given enough information about the hospital/unit where your baby was being transferred (such as location and facilities)?	1 Yes, definitely	60.3%	61.0%	62.8%	1	4	0.96	58.4%	61.2%	65.5%	60.1%	4	6	0.63	60.2%	65.2%	3	2	0.23
	2 Yes, to some extent	29.7%	29.9%	27.9%	1	4	0.96	30.2%	29.1%	25.6%	31.3%	4	6	0.63	30.5%	24.7%	3	2	0.23
	3 No	10.0%	9.1%	9.3%	1	4	0.96	11.4%	9.7%	8.9%	8.6%	4	6	0.63	9.3%	10.1%	3	2	0.23
D1 When you visited the unit, did the staff caring for your baby introduce themselves to you?	1 Yes, all of the staff introduced themselves	55.7%	55.7%	58.7%	7	4	0.12	55.4%	55.7%	57.6%	57.4%	10	6	0.11	57.0%	54.7%	3	2	0.28
	2 Some of the staff introduced themselves	37.3%	37.4%	35.0%	7	4	0.12	36.5%	37.7%	36.3%	36.3%	10	6	0.11	36.4%	38.1%	3	2	0.28
	3 Very few or none of the staff introduced themselves	7.0%	6.9%	6.3%	7	4	0.12	8.1%	6.7%	6.1%	6.3%	10	6	0.11	6.6%	7.2%	3	2	0.28
D2 Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?	1 Yes	83.9%	86.0%	87.4%	13	2	.002*	84.1%	85.8%	86.4%	87.2%	10	3	0.02	85.9%	86.3%	0	1	0.70
	2 No	16.1%	14.0%	12.6%	13	2	.002*	15.9%	14.2%	13.6%	12.8%	10	3	0.02	14.1%	13.7%	0	1	0.70

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
D3 Did staff keep you up to date with your baby's condition and progress?	1 Yes, always or nearly always	78.4%	78.5%	79.4%	3	4	0.62	72.8%	79.1%	80.7%	81.6%	70	6	.000*	78.8%	78.4%	1	2	0.67
	2 Yes, sometimes	18.7%	18.4%	17.3%	3	4	0.62	22.7%	17.5%	16.6%	16.3%	70	6	.000*	18.0%	18.8%	1	2	0.67
	3 No	2.9%	3.2%	3.3%	3	4	0.62	4.6%	3.4%	2.8%	2.1%	70	6	.000*	3.2%	2.9%	1	2	0.67
D4 Were you able to talk to staff on the unit about your worries and concerns?	1 Yes, always or nearly always	75.2%	76.0%	76.4%	1	4	0.89	69.4%	75.2%	78.0%	79.9%	84	6	.000*	76.7%	72.0%	16	2	.000*
	2 Yes, sometimes	21.6%	21.0%	20.8%	1	4	0.89	26.1%	22.3%	19.5%	17.6%	84	6	.000*	20.5%	24.2%	16	2	.000*
	3 No	3.2%	3.0%	2.9%	1	4	0.89	4.5%	2.5%	2.5%	2.6%	84	6	.000*	2.8%	3.8%	16	2	.000*
D5 Were you able to speak to a doctor about your baby as much as you wanted?	1 Yes, always or nearly always	34.6%	35.2%	36.4%	3	4	0.52	34.5%	34.3%	35.7%	37.0%	27	6	.000*	33.8%	43.7%	55	2	.000*
	2 Yes, to some extent	46.4%	45.4%	45.7%	3	4	0.52	44.0%	45.3%	46.4%	46.8%	27	6	.000*	46.6%	41.5%	55	2	.000*
	3 No	19.1%	19.4%	18.0%	3	4	0.52	21.5%	20.4%	17.9%	16.1%	27	6	.000*	19.6%	14.9%	55	2	.000*
D6 Were the nurses on the unit sensitive to your emotions and feelings?	1 Yes, always or nearly always	73.1%	72.6%	73.5%	1	4	0.89	66.0%	72.8%	74.7%	77.3%	87	6	.000*	74.4%	65.7%	47.710	2	.000*
	2 Yes, sometimes	22.6%	22.9%	22.3%	1	4	0.89	27.6%	22.9%	21.5%	19.5%	87	6	.000*	21.5%	28.8%	47.710	2	.000*
	3 No	4.3%	4.5%	4.2%	1	4	0.89	6.4%	4.3%	3.8%	3.2%	87	6	.000*	4.1%	5.5%	47.710	2	.000*
D7 Were the doctors on the unit sensitive to your emotions and feelings?	1 Yes, always or nearly always	60.8%	61.9%	66.5%	24	4	.000*	58.5%	62.6%	64.4%	66.2%	39	6	.000*	63.2%	61.9%	1	2	0.61
	2 Yes, sometimes	31.9%	32.2%	28.3%	24	4	.000*	33.7%	32.4%	29.4%	28.6%	39	6	.000*	30.7%	32.1%	1	2	0.61
	3 No	7.3%	5.9%	5.2%	24	4	.000*	7.8%	5.0%	6.2%	5.2%	39	6	.000*	6.0%	6.0%	1	2	0.61
D8 In your opinion, was important information about your baby passed on from one member of staff to another?	1 Yes, always or nearly always	70.5%	71.0%	70.4%	1	4	0.92	63.9%	69.6%	72.4%	75.6%	83	6	.000*	71.4%	66.8%	13	2	.002*
	2 Yes, sometimes	23.8%	23.8%	24.1%	1	4	0.92	29.0%	25.1%	22.3%	20.2%	83	6	.000*	23.3%	26.9%	13	2	.002*
	3 No, information was not passed on	5.7%	5.2%	5.5%	1	4	0.92	7.1%	5.3%	5.3%	4.2%	83	6	.000*	5.2%	6.3%	13	2	.002*

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
D9 Did staff give you conflicting information about your baby's condition or care?	1 Yes, often	18.5%	17.5%	18.3%	5	4	0.26	30.1%	18.7%	14.3%	11.2%	416	6	.000*	16.3%	26.9%	94	2	.000*
	2 Yes, sometimes	26.8%	25.6%	27.3%	5	4	0.26	30.6%	25.7%	25.1%	24.8%	416	6	.000*	27.0%	23.2%	94	2	.000*
	3 No, not at all	54.7%	56.9%	54.4%	5	4	0.26	39.3%	55.5%	60.5%	64.0%	416	6	.000*	56.7%	49.9%	94	2	.000*
D10 As far as you know, did staff wash or clean their hands before touching your baby?	1 Yes, always or nearly always	92.6%	92.6%	93.2%	3	4	0.53	91.2%	93.2%	92.7%	93.7%	13	6	0.05	93.4%	89.4%	29	2	.000*
	2 Yes, to some extent	6.2%	6.5%	6.1%	3	4	0.53	7.5%	5.9%	6.4%	5.7%	13	6	0.05	5.8%	9.1%	29	2	.000*
	3 No	1.1%	.9%	.7%	3	4	0.53	1.3%	.9%	1.0%	.6%	13	6	0.05	.8%	1.5%	29	2	.000*
D11 Did staff refer to your baby by his/her first name?	1 Yes, always or nearly always	86.2%	85.0%	83.8%	6	4	0.19	80.3%	84.4%	86.2%	87.9%	61	6	.000*	86.7%	73.8%	158	2	.000*
	2 Yes, to some extent	10.7%	11.3%	12.4%	6	4	0.19	14.3%	11.8%	11.2%	9.2%	61	6	.000*	10.5%	17.8%	158	2	.000*
	3 No	3.1%	3.8%	3.7%	6	4	0.19	5.4%	3.8%	2.6%	2.9%	61	6	.000*	2.8%	8.4%	158	2	.000*
D12 Overall, did staff treat you with respect and courtesy?	1 Yes, always or nearly always	85.0%	85.9%	86.1%	2	4	0.67	78.3%	86.4%	87.8%	89.4%	136	6	.000*	86.3%	82.8%	17	2	.000*
	2 Yes, sometimes	13.3%	12.4%	12.0%	2	4	0.67	18.8%	12.0%	10.6%	9.5%	136	6	.000*	11.9%	15.7%	17	2	.000*
	3 No	1.7%	1.7%	1.9%	2	4	0.67	2.9%	1.6%	1.7%	1.0%	136	6	.000*	1.8%	1.5%	17	2	.000*
D13 Overall, did you have confidence and trust in the staff caring for your baby?	1 Yes, always or nearly always	85.3%	85.1%	86.4%	3	4	0.64	80.4%	86.0%	86.4%	88.4%	67	6	.000*	86.5%	80.6%	37	2	.000*
	2 Yes, sometimes	12.4%	12.5%	11.5%	3	4	0.64	16.4%	11.7%	11.7%	9.7%	67	6	.000*	11.4%	16.0%	37	2	.000*
	3 No	2.3%	2.3%	2.1%	3	4	0.64	3.3%	2.2%	1.9%	1.9%	67	6	.000*	2.0%	3.4%	37	2	.000*

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
E1 Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	1 Yes, definitely	82.4%	81.1%	80.4%	6	4	0.21	76.3%	81.7%	83.0%	83.1%	47	6	.000*	81.0%	82.5%	11	2	.005*
	2 Yes, to some extent	12.4%	14.1%	14.4%	6	4	0.21	17.1%	13.7%	12.2%	12.6%	47	6	.000*	13.7%	14.2%	11	2	.005*
	3 No, I was not involved as much as I wanted	5.2%	4.8%	5.2%	6	4	0.21	6.6%	4.6%	4.8%	4.3%	47	6	.000*	5.3%	3.3%	11	2	.005*
E2 Was your partner or companion involved as much as they wanted in the day-to-day care of your baby, such as nappy changing and feeding?	1 Yes, definitely	78.8%	76.4%	74.6%	12	4	0.02	68.3%	77.4%	78.8%	79.9%	109	6	.000*	77.2%	72.9%	13	2	.002*
	2 Yes, to some extent	15.9%	17.9%	19.3%	12	4	0.02	23.1%	17.0%	16.6%	15.8%	109	6	.000*	17.3%	21.0%	13	2	.002*
	3 No, they were not involved as much as they wanted to be	5.3%	5.7%	6.0%	12	4	0.02	8.6%	5.6%	4.6%	4.3%	109	6	.000*	5.6%	6.1%	13	2	.002*
E3 Were you encouraged to touch, hold and comfort your baby?	1 Yes, definitely	76.5%	76.5%	77.7%	2	4	0.81	69.1%	77.3%	78.1%	81.7%	125	6	.000*	75.4%	84.7%	63	2	.000*
	2 Yes, to some extent	18.4%	18.6%	17.7%	2	4	0.81	22.9%	18.1%	17.9%	14.9%	125	6	.000*	19.3%	12.4%	63	2	.000*
	3 No	5.1%	4.9%	4.7%	2	4	0.81	8.0%	4.6%	4.0%	3.4%	125	6	.000*	5.3%	2.9%	63	2	.000*
E4 Did you have as much 'kangaroo care' (skin- to-skin contact) with your baby as you wanted?	1 Yes, definitely	50.6%	49.9%	49.0%	11	6	0.08	42.9%	48.5%	52.2%	54.2%	102	9	.000*	47.4%	61.4%	114	3	.000*
	2 Yes, to some extent	20.3%	21.3%	21.2%	11	6	0.08	19.6%	22.0%	21.0%	21.3%	102	9	.000*	21.3%	19.9%	114	3	.000*
	3 No, not as much kangaroo care as wanted	20.0%	17.7%	19.4%	11	6	0.08	24.7%	18.4%	17.8%	15.5%	102	9	.000*	20.4%	10.7%	114	3	.000*
	5 I did not know about kangaroo care	9.0%	11.1%	10.4%	11	6	0.08	12.9%	11.1%	9.0%	9.1%	102	9	.000*	10.8%	8.0%	114	3	.000*

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		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
E5 Did the doctors and nurses include you in discussions about your baby's care and treatment?	1 Yes, always	54.5%	54.4%	54.4%	1	4	0.88	50.7%	55.5%	54.7%	56.5%	24	6	.001*	53.8%	57.9%	9	2	.010*
	2 Yes, sometimes	35.9%	35.2%	35.7%	1	4	0.88	38.1%	34.0%	36.5%	33.6%	24	6	.001*	36.0%	33.1%	9	2	.010*
	3 No	9.7%	10.4%	9.8%	1	4	0.88	11.2%	10.5%	8.8%	9.8%	24	6	.001*	10.2%	9.0%	9	2	.010*
E6 Were you told about any changes in your baby's condition or care?	1 Yes, always or nearly always	78.4%	77.7%	75.4%	8	4	0.09	73.2%	76.6%	79.3%	79.2%	37	6	.000*	77.2%	77.2%	1	2	0.55
	2 Yes, to some extent	18.0%	18.8%	20.8%	8	4	0.09	21.8%	19.6%	18.1%	17.6%	37	6	.000*	19.3%	18.7%	1	2	0.55
	3 No, I was not told about changes	3.5%	3.5%	3.8%	8	4	0.09	4.9%	3.8%	2.6%	3.3%	37	6	.000*	3.5%	4.0%	1	2	0.55
E7 When a ward round was taking place, were you allowed to be present when your baby was being discussed?	1 Yes, always or nearly always	69.6%	62.2%	59.0%	92	4	.000*	60.5%	64.0%	66.0%	61.7%	16	6	0.01	65.4%	50.4%	107	2	.000*
	2 Yes, to some extent	18.1%	18.0%	17.5%	92	4	.000*	19.7%	17.0%	16.3%	18.2%	16	6	0.01	16.9%	22.8%	107	2	.000*
	3 No, I was not allowed to be there	12.3%	19.8%	23.5%	92	4	.000*	19.9%	19.0%	17.7%	20.1%	16	6	0.01	17.7%	26.8%	107	2	.000*
E8 Did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	1 Yes, always or nearly always	59.1%	55.4%	52.4%	23	4	.000*	48.4%	55.1%	57.6%	59.1%	71	6	.000*	56.7%	49.0%	30	2	.000*
	2 Yes, sometimes	21.7%	24.0%	25.0%	23	4	.000*	25.5%	24.6%	22.5%	22.9%	71	6	.000*	23.1%	26.8%	30	2	.000*
	3 No	19.2%	20.6%	22.6%	23	4	.000*	26.1%	20.3%	19.9%	18.0%	71	6	.000*	20.2%	24.2%	30	2	.000*
E9 Overall, did staff help you feel confident in caring for your baby?	1 Yes, definitely	77.0%	76.6%	76.3%	1	4	0.91	70.8%	76.9%	79.0%	79.0%	66	6	.000*	76.7%	76.2%	2	2	0.36
	2 Yes, to some extent	18.8%	19.5%	19.5%	1	4	0.91	23.0%	19.3%	18.0%	17.6%	66	6	.000*	19.2%	20.2%	2	2	0.36
	3 No	4.2%	3.9%	4.2%	1	4	0.91	6.1%	3.9%	3.0%	3.4%	66	6	.000*	4.2%	3.5%	2	2	0.36

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E10 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?	1 Yes, definitely	78.2%	75.9%	74.5%	10	4	0.04	72.5%	76.5%	77.3%	76.9%	18	6	.006*	75.0%	81.0%	22	2	.000*
	2 Yes, to some extent	15.2%	17.7%	18.0%	10	4	0.04	19.1%	16.2%	17.2%	16.6%	18	6	.006*	17.9%	14.0%	22	2	.000*
	3 No	6.7%	6.4%	7.5%	10	4	0.04	8.4%	7.3%	5.5%	6.5%	18	6	.006*	7.2%	5.0%	22	2	.000*
E11 Were you given the equipment you needed, such as a breast pump and sterilisation equipment?	1 Yes, definitely	84.8%	84.4%	84.1%	1	4	0.92	82.3%	83.1%	86.5%	84.8%	21	6	.002*	84.4%	84.1%	1	2	0.75
	2 Yes, to some extent	8.2%	8.8%	8.7%	1	4	0.92	8.6%	9.3%	7.6%	9.1%	21	6	.002*	8.7%	8.4%	1	2	0.75
	3 No	7.0%	6.8%	7.2%	1	4	0.92	9.0%	7.6%	5.9%	6.1%	21	6	.002*	6.9%	7.4%	1	2	0.75
E12 Were you given enough privacy for expressing milk for your baby?	1 Yes, definitely	76.9%	76.1%	77.8%	9	6	0.15	73.1%	77.2%	78.5%	77.8%	22	9	.008*	75.7%	81.8%	23	3	.000*
	2 Yes, to some extent	15.5%	17.1%	15.9%	9	6	0.15	18.0%	16.9%	15.1%	15.5%	22	9	.008*	17.2%	12.4%	23	3	.000*
	3 No, and it bothered me	4.8%	4.7%	3.6%	9	6	0.15	6.0%	3.8%	4.1%	4.0%	22	9	.008*	4.6%	3.4%	23	3	.000*
	4 No, but I did not mind	2.8%	2.1%	2.7%	9	6	0.15	2.9%	2.1%	2.3%	2.7%	22	9	.008*	2.5%	2.4%	23	3	.000*
E13 Were there facilities on the neonatal unit for the storage of breast milk?	1 Yes	99.2%	98.8%	98.8%	2	2	0.44	98.1%	98.9%	99.1%	99.3%	13	3	.005*	99.3%	97.2%	41	1	.000*
	2 No	.8%	1.2%	1.2%	2	2	0.44	1.9%	1.1%	.9%	.7%	13	3	.005*	.7%	2.8%	41	1	.000*
E14 If you wanted to breastfeed your baby were you given enough support to do this from neonatal staff?	1 Yes, definitely	75.7%	73.4%	73.3%	5	4	0.27	69.9%	72.2%	75.7%	76.3%	49	6	.000*	72.8%	79.0%	22	2	.000*
	2 Yes, to some extent	16.9%	19.0%	19.5%	5	4	0.27	18.8%	19.8%	18.3%	17.8%	49	6	.000*	19.3%	15.6%	22	2	.000*
	3 No	7.4%	7.6%	7.2%	5	4	0.27	11.3%	7.9%	5.9%	5.9%	49	6	.000*	7.9%	5.4%	22	2	.000*

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
E15 Were you given enough privacy for breast feeding your baby?	1 Yes, definitely	67.0%	66.5%	66.7%	2	6	0.89	64.1%	66.5%	68.0%	67.2%	23	9	.006*	64.8%	75.0%	50	3	.000*
	2 Yes, to some extent	21.6%	22.5%	21.8%	2	6	0.89	23.3%	22.7%	21.5%	21.3%	23	9	.006*	23.3%	16.8%	50	3	.000*
	3 No, and it bothered me	6.5%	6.4%	6.2%	2	6	0.89	8.1%	6.8%	5.8%	5.5%	23	9	.006*	6.7%	5.0%	50	3	.000*
	4 No, but I did not mind	4.9%	4.5%	5.3%	2	6	0.89	4.5%	4.0%	4.7%	6.0%	23	9	.006*	5.2%	3.2%	50	3	.000*
E16 If you bottle fed your baby (formula milk) were you given enough support to do this from neonatal staff?	1 Yes, definitely	75.8%	74.1%	73.5%	4	4	0.43	69.3%	73.6%	75.5%	78.9%	40	6	.000*	73.7%	77.3%	6	2	0.06
	2 Yes, to some extent	19.6%	20.6%	20.6%	4	4	0.43	24.5%	21.7%	19.5%	16.2%	40	6	.000*	20.8%	18.2%	6	2	0.06
	3 No	4.6%	5.3%	5.9%	4	4	0.43	6.2%	4.7%	5.0%	4.9%	40	6	.000*	5.4%	4.5%	6	2	0.06
F1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?	1 Yes, always or nearly always	64.8%	62.4%	61.0%	20	6	.003*	57.9%	63.7%	63.8%	64.2%	70	9	.000*	62.9%	60.8%	12	3	.006*
	2 Yes, to some extent	21.3%	24.5%	23.2%	20	6	.003*	28.6%	22.4%	22.1%	21.0%	70	9	.000*	22.7%	26.5%	12	3	.006*
	3 No	6.9%	6.9%	7.6%	20	6	.003*	8.5%	7.0%	6.5%	6.7%	70	9	.000*	7.2%	6.8%	12	3	.006*
	4 No, but I did not mind	7.0%	6.3%	8.2%	20	6	.003*	5.0%	6.9%	7.7%	8.2%	70	9	.000*	7.2%	5.9%	12	3	.006*
F3 Was there enough space for you to sit alongside your baby's cot in the unit?	1 Yes, always or nearly always	69.0%	64.0%	64.7%	22	4	.000*	59.8%	66.0%	66.6%	68.6%	54	6	.000*	65.1%	67.3%	4	2	0.16
	2 Yes, sometimes	27.4%	32.5%	32.3%	22	4	.000*	35.2%	31.1%	30.6%	28.5%	54	6	.000*	31.6%	29.1%	4	2	0.16
	3 No, never	3.6%	3.5%	3.0%	22	4	.000*	5.0%	2.9%	2.8%	2.9%	54	6	.000*	3.3%	3.6%	4	2	0.16
F4 In your opinion, was there adequate security on the neonatal unit?	1 Yes, definitely	80.6%	76.2%	73.8%	38	4	.000*	73.5%	77.8%	77.1%	77.8%	37	6	.000*	76.6%	76.3%	1	2	0.65
	2 Yes, to some extent	16.3%	19.2%	22.1%	38	4	.000*	20.3%	18.7%	19.6%	18.7%	37	6	.000*	19.2%	19.9%	1	2	0.65
	3 No	3.1%	4.6%	4.2%	38	4	.000*	6.2%	3.5%	3.4%	3.5%	37	6	.000*	4.2%	3.7%	1	2	0.65

		Type of unit baby was discharged from			Pearson Chi-square Tests			Age group from response or sample age if missing				Pearson Chi-square Tests			Ethnic group from response data else sample information if response missing		Pearson Chi-square Tests		
		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
F5 If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?	1 Yes, always or nearly always	46.3%	42.8%	44.1%	6	4	0.22	39.4%	42.1%	45.8%	48.6%	40	6	.000*	45.3%	37.7%	26	2	.000*
	2 Yes, sometimes	16.0%	17.2%	16.8%	6	4	0.22	17.8%	16.6%	17.2%	15.6%	40	6	.000*	16.7%	16.9%	26	2	.000*
	3 No	37.7%	40.0%	39.1%	6	4	0.22	42.8%	41.3%	37.0%	35.8%	40	6	.000*	38.0%	45.4%	26	2	.000*
F6 Were you able to visit your baby on the unit as much as you wanted to?	1 Yes, definitely	90.1%	89.3%	88.8%	3	4	0.52	88.1%	89.6%	90.4%	89.3%	6	6	0.37	89.4%	89.0%	0	2	0.82
	2 Yes, to some extent	7.4%	8.4%	8.6%	3	4	0.52	9.3%	8.0%	7.5%	8.2%	6	6	0.37	8.1%	8.6%	0	2	0.82
	3 No	2.5%	2.3%	2.5%	3	4	0.52	2.6%	2.3%	2.1%	2.5%	6	6	0.37	2.4%	2.4%	0	2	0.82
F8 If you had your other children with you when visiting the unit, was there somewhere they could play?	2 Yes, there was a supervised play room/area	10.1%	8.2%	8.2%	97	6	.000*	10.5%	10.8%	7.4%	7.7%	46	9	.000*	6.8%	18.0%	119	3	.000*
	3 Yes, there was an unsupervised play room/area	56.8%	49.9%	41.3%	97	6	.000*	40.8%	48.3%	50.4%	51.9%	46	9	.000*	51.5%	35.7%	119	3	.000*
	4 No, there was nowhere for them to play	26.9%	33.6%	34.6%	97	6	.000*	33.3%	31.7%	33.1%	31.5%	46	9	.000*	32.5%	31.2%	119	3	.000*
	5 Children were not allowed to visit the unit	6.3%	8.3%	15.8%	97	6	.000*	15.4%	9.2%	9.1%	8.9%	46	9	.000*	9.2%	15.0%	119	3	.000*
F9 Were you able to contact the unit by telephone whenever you needed to?	1 Yes, always or nearly always	93.6%	91.8%	90.2%	14	4	.007*	89.1%	92.3%	92.7%	92.7%	24	6	.000*	93.0%	85.6%	75	2	.000*
	2 Yes, sometimes	4.9%	6.0%	7.1%	14	4	.007*	7.5%	5.8%	5.6%	5.5%	24	6	.000*	5.3%	9.8%	75	2	.000*
	3 No, never	1.5%	2.2%	2.7%	14	4	.007*	3.5%	1.9%	1.7%	1.8%	24	6	.000*	1.7%	4.6%	75	2	.000*

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		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
G1 Were you given enough written information to help you understand your baby's condition and treatment?	1 Yes, definitely	39.2%	40.3%	39.4%	3	6	0.83	37.8%	39.3%	39.6%	42.6%	30	9	.001*	38.8%	44.6%	31	3	.000*
	2 Yes, to some extent	21.3%	20.8%	21.6%	3	6	0.83	21.0%	20.5%	22.0%	20.8%	30	9	.001*	20.9%	22.5%	31	3	.000*
	3 No, I was not given enough written information	11.6%	12.1%	11.2%	3	6	0.83	14.1%	11.8%	11.8%	9.5%	30	9	.001*	11.8%	11.2%	31	3	.000*
	4 I did not get any written information	27.8%	26.8%	27.8%	3	6	0.83	27.0%	28.5%	26.7%	27.2%	30	9	.001*	28.5%	21.8%	31	3	.000*
G2 If you needed help understanding written or spoken English, was information given in a language you could understand?	1 Yes	82.0%	76.1%	78.9%	3	2	0.22	76.2%	78.7%	77.6%	80.9%	2	3	0.64	79.6%	76.5%	1	1	0.26
	2 No	18.0%	23.9%	21.1%	3	2	0.22	23.8%	21.3%	22.4%	19.1%	2	3	0.64	20.4%	23.5%	1	1	0.26
G3 When you asked questions about your baby's condition and treatment, did you get answers you could understand?	1 Yes, always or nearly always	71.8%	72.6%	73.3%	2	4	0.75	61.2%	71.6%	76.3%	79.5%	225	6	.000*	72.6%	73.0%	0	2	0.81
	2 Yes, sometimes	25.2%	24.7%	23.7%	2	4	0.75	34.2%	25.0%	21.4%	19.0%	225	6	.000*	24.5%	24.4%	0	2	0.81
	3 No	3.0%	2.7%	2.9%	2	4	0.75	4.6%	3.4%	2.3%	1.6%	225	6	.000*	2.9%	2.6%	0	2	0.81
G4 Did a member of staff explain the purpose of any tests your baby had in a way you could understand?	1 Yes, always or nearly always	79.1%	79.1%	78.6%	1	4	0.94	71.1%	77.9%	82.5%	83.2%	141	6	.000*	79.4%	76.8%	7	2	0.03
	2 Yes, sometimes	18.4%	18.2%	18.6%	1	4	0.94	24.1%	19.7%	15.6%	15.1%	141	6	.000*	17.9%	20.8%	7	2	0.03
	3 No	2.5%	2.7%	2.8%	1	4	0.94	4.8%	2.5%	2.0%	1.8%	141	6	.000*	2.7%	2.5%	7	2	0.03
G5 If your baby had any surgery, did a member of staff explain the operation and its outcome in a way you could understand?	1 Yes, always or nearly always	73.8%	71.8%	82.6%	15	4	.005*	66.8%	78.9%	82.4%	81.0%	20	6	.003*	81.3%	66.7%	19	2	.000*
	2 Yes, sometimes	12.8%	15.7%	12.1%	15	4	.005*	17.6%	14.3%	9.2%	12.2%	20	6	.003*	11.0%	19.4%	19	2	.000*
	3 No	13.5%	12.5%	5.3%	15	4	.005*	15.6%	6.8%	8.5%	6.8%	20	6	.003*	7.7%	14.0%	19	2	.000*

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G6 Did you read your baby's medical notes (not just the nursing notes) while they were in the neonatal unit?	1 Yes	43.4%	46.4%	40.9%	32	6	.000*	49.7%	42.4%	42.0%	42.4%	59	9	.000*	43.2%	48.1%	34	3	.000*
	2 No, but I wanted to read them	18.3%	19.1%	22.5%	32	6	.000*	20.6%	20.8%	20.0%	18.8%	59	9	.000*	19.5%	22.4%	34	3	.000*
	3 No, but I did not want to read them	8.6%	7.9%	8.6%	32	6	.000*	6.1%	8.2%	9.1%	9.5%	59	9	.000*	8.7%	6.2%	34	3	.000*
	4 I did not know about or see the medical notes	29.6%	26.6%	28.0%	32	6	.000*	23.7%	28.7%	28.9%	29.3%	59	9	.000*	28.6%	23.4%	34	3	.000*
G7 Were you offered emotional support or counselling services?	1 Yes	17.4%	16.4%	21.2%	28	4	.000*	16.9%	18.1%	16.9%	20.3%	22	6	.001*	17.4%	22.0%	24	2	.000*
	2 No, but I would have liked to have been offered this	25.2%	25.9%	24.4%	28	4	.000*	24.9%	27.4%	26.1%	23.2%	22	6	.001*	25.1%	26.6%	24	2	.000*
	3 I did not need any emotional support or counselling	57.3%	57.7%	54.3%	28	4	.000*	58.1%	54.5%	57.1%	56.5%	22	6	.001*	57.6%	51.4%	24	2	.000*
G8 Were you given information about any help you could get with travelling expenses, parking costs or food vouchers?	1 Yes, definitely	27.3%	24.9%	22.6%	16	4	.002*	21.2%	23.9%	26.2%	27.6%	53	6	.000*	25.5%	20.9%	39	2	.000*
	2 Yes, to some extent	20.4%	23.2%	22.2%	16	4	.002*	19.1%	22.7%	23.6%	23.4%	53	6	.000*	23.1%	18.0%	39	2	.000*
	3 No	52.3%	51.9%	55.2%	16	4	.002*	59.8%	53.4%	50.3%	49.0%	53	6	.000*	51.4%	61.1%	39	2	.000*

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G9 Did staff give you any information about parent support groups, such as Bliss or other local groups?	1 Yes, staff gave me this information	30.0%	31.8%	32.1%	3	4	0.55	29.3%	30.2%	32.5%	33.6%	93	6	.000*	31.4%	31.5%	30	2	.000*
	2 No, but this information was available in the unit (e.g. a leaflet in the parents' room)	35.2%	34.4%	33.6%	3	4	0.55	28.7%	33.9%	36.3%	37.5%	93	6	.000*	35.5%	28.5%	30	2	.000*
	3 No, I did not get this information	34.7%	33.8%	34.2%	3	4	0.55	42.0%	35.9%	31.2%	28.8%	93	6	.000*	33.1%	40.0%	30	2	.000*
H1 In total, how long did your baby stay in neonatal care (include all the hospitals they stayed in)?	1 Up to one week	46.9%	48.7%	45.9%	39	8	.000*	46.8%	49.2%	47.4%	46.0%	18	12	0.12	48.5%	41.5%	84	4	.000*
	2 More than 1 week but less than 4 weeks	36.7%	35.3%	35.6%	39	8	.000*	35.5%	34.3%	35.6%	37.2%	18	12	0.12	36.1%	33.8%	84	4	.000*
	3 More than 4 weeks but less than 8 weeks	10.6%	9.9%	9.7%	39	8	.000*	10.0%	10.1%	10.9%	9.5%	18	12	0.12	9.1%	14.9%	84	4	.000*
	4 More than 8 weeks but less than 12 weeks	4.0%	3.7%	4.7%	39	8	.000*	4.3%	4.1%	3.9%	4.1%	18	12	0.12	3.9%	5.0%	84	4	.000*
	5 More than 12 weeks	1.7%	2.4%	4.1%	39	8	.000*	3.4%	2.3%	2.2%	3.2%	18	12	0.12	2.4%	4.7%	84	4	.000*
H2 In your opinion, was your baby's stay in neonatal care...	1 Shorter than was needed	3.9%	5.1%	5.4%	11	4	0.03	6.1%	5.1%	4.4%	4.2%	44	6	.000*	4.1%	9.1%	71	2	.000*
	2 About right	86.4%	86.9%	86.0%	11	4	0.03	82.4%	86.7%	88.0%	88.4%	44	6	.000*	87.0%	84.1%	71	2	.000*
	3 Longer than was needed	9.6%	8.0%	8.6%	11	4	0.03	11.5%	8.2%	7.5%	7.4%	44	6	.000*	8.9%	6.8%	71	2	.000*

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		SCBU	LNU	NICU	Chi-Square	df	Sig.	16-27	28-31	32-35	36 and over	Chi-Square	df	Sig.	White	Non-White	Chi-Square	df	Sig.
H3 When your baby was discharged from the neonatal unit, where did they go next?	1 A hospital maternity ward	27.4%	28.8%	30.0%	108	6	.000*	27.0%	30.0%	28.4%	29.3%	12	9	0.24	29.7%	24.4%	22	3	.000*
	2 Another ward in the hospital	2.3%	3.0%	6.8%	108	6	.000*	4.1%	4.6%	3.7%	3.6%	12	9	0.24	3.7%	5.2%	22	3	.000*
	3 Home	69.5%	67.7%	62.0%	108	6	.000*	67.8%	64.5%	67.0%	66.5%	12	9	0.24	65.8%	69.3%	22	3	.000*
	4 Somewhere else	.9%	.5%	1.2%	108	6	.000*	1.0%	.9%	.8%	.6%	12	9	0.24	.8%	1.1%	22	3	.000*
H4 Were you offered accommodation overnight at the hospital before your baby came home?	1 Yes	82.7%	78.9%	78.1%	17	4	.002*	78.8%	80.8%	78.2%	81.3%	20	6	.003*	81.4%	71.5%	61	2	.000*
	2 No, but I would have liked it	2.7%	4.6%	4.5%	17	4	.002*	5.6%	4.0%	3.9%	2.9%	20	6	.003*	3.4%	7.2%	61	2	.000*
	3 No, but I did not want or need it	14.6%	16.5%	17.5%	17	4	.002*	15.6%	15.2%	17.9%	15.8%	20	6	.003*	15.2%	21.3%	61	2	.000*
H5 Did you feel prepared for your baby's discharge from neonatal care?	1 Yes, definitely	76.2%	74.9%	72.4%	13	4	0.01	76.5%	74.8%	74.6%	72.5%	13	6	0.04	74.6%	73.7%	1	2	0.73
	2 Yes, to some extent	20.2%	21.4%	23.0%	13	4	0.01	19.6%	21.4%	22.0%	23.0%	13	6	0.04	21.5%	22.2%	1	2	0.73
	3 No	3.5%	3.6%	4.6%	13	4	0.01	3.9%	3.8%	3.3%	4.5%	13	6	0.04	3.9%	4.1%	1	2	0.73
H6 Did your baby need any special equipment when s/he was discharged from the unit?	1 Yes	7.7%	8.4%	11.9%	34	2	.000*	11.1%	8.7%	9.2%	8.7%	10	3	0.02	9.1%	10.3%	2	1	0.17
	2 No	92.3%	91.6%	88.1%	34	2	.000*	88.9%	91.3%	90.8%	91.3%	10	3	0.02	90.9%	89.7%	2	1	0.17
H7 Were you given enough information and guidance on using the equipment when your baby left the neonatal unit?	1 Yes, definitely	82.2%	76.9%	78.0%	4	4	0.43	72.5%	79.3%	80.4%	82.4%	13	6	0.04	78.9%	76.3%	1	2	0.49
	2 Yes, to some extent	12.1%	16.9%	17.6%	4	4	0.43	22.9%	13.3%	15.0%	12.4%	13	6	0.04	15.6%	19.2%	1	2	0.49
	3 No	5.7%	6.1%	4.4%	4	4	0.43	4.7%	7.4%	4.7%	5.2%	13	6	0.04	5.6%	4.5%	1	2	0.49

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H8 Were you given enough information on what to expect in terms of your baby's progress and recovery?	1 Yes, definitely	53.5%	53.2%	55.4%	8	4	0.11	51.5%	55.3%	54.3%	54.8%	56	6	.000*	52.7%	60.5%	31	2	.000*
	2 Yes, to some extent	30.5%	32.0%	30.9%	8	4	0.11	29.0%	30.7%	32.6%	32.6%	56	6	.000*	32.2%	27.1%	31	2	.000*
	3 No	16.0%	14.7%	13.6%	8	4	0.11	19.6%	14.0%	13.1%	12.6%	56	6	.000*	15.1%	12.4%	31	2	.000*
H11 If you saw a health visitor, did s/he have enough information about the development of babies who had received neonatal care?	1 Yes, definitely	40.3%	38.6%	38.3%	3	4	0.59	42.3%	37.4%	37.6%	38.5%	24	6	.001*	36.6%	51.0%	121	2	.000*
	2 Yes, to some extent	33.6%	34.6%	35.3%	3	4	0.59	31.3%	35.7%	34.2%	36.7%	24	6	.001*	35.2%	31.2%	121	2	.000*
	3 No	26.1%	26.8%	26.4%	3	4	0.59	26.4%	26.9%	28.2%	24.8%	24	6	.001*	28.2%	17.7%	121	2	.000*
H12 Overall, after your baby arrived home, did you get enough support from health professionals?	1 Yes, definitely	60.0%	56.4%	60.2%	14	4	.008*	56.8%	58.1%	58.3%	60.3%	16	6	0.01	58.8%	56.9%	3	2	0.22
	2 Yes, to some extent	30.3%	33.2%	30.8%	14	4	.008*	31.6%	31.6%	32.9%	30.8%	16	6	0.01	31.4%	33.6%	3	2	0.22
	3 No	9.7%	10.4%	9.0%	14	4	.008*	11.6%	10.3%	8.8%	8.9%	16	6	0.01	9.9%	9.5%	3	2	0.22
J1 Did your baby stay in a neonatal unit in more than one hospital?	1 Yes	19.3%	10.0%	10.8%	127	2	.000*	12.6%	11.2%	13.8%	12.6%	7	3	0.08	11.8%	16.2%	21	1	.000*
	2 No	80.7%	90.0%	89.2%	127	2	.000*	87.4%	88.8%	86.2%	87.4%	7	3	0.08	88.2%	83.8%	21	1	.000*

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