Neonatal Network Northern Ireland (NNNI)
Regional Discharge Questionnaire: One Year On.

Produced on behalf of the NNNI Parent Engagement Group by:

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ISBN: 9781909131392

Published: July 2015, NICORE.

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Executive Summary

Aim

The Regional Discharge Questionnaire (RDQ) is a service improvement tool which was developed to provide a mechanism for user input to the service improvement plans of the Health & Social Care Trusts and the Neonatal Network Northern Ireland (NNNI). It is the foundation to the Network approach to securing a partnership with users in a difficult delivery area. The NNNI Parental Engagement Group (PEG) has evolved from the existing RDQ Task and Finish Group in order to facilitate the wider function (Appendix One). This PEG was established to have ongoing oversight of the analysis and dissemination of the RDQ as part of the boarder Parental Engagement Strategy of the NNNI.

Representativeness

During the study time period (1st April 2014 to 31st March 2015) 1974 live infants were discharged from neonatal units (NNUs) in Northern Ireland (NI).[1] Across the seven NNUs in NI coverage (number of questionnaires returned as a percentage of the number of live discharges during the study time period) ranged from 18.9% to 42.4%, with an overall NNNI coverage of 31.2%.

The recent 2014 Picker Institute Europe report on parents' experiences of neonatal care survey[2] (which took place during a similar time period involving 88 NNUs from 13 neonatal networks in England) stated an overall response rate of 37.6% for a sample of 6000 parents who completed the survey after discharge home.[2] This is comparable to the NNNI coverage (proxy for response rate) of 31.2%, although this may be under-estimated due to some difficulties with RDQ distribution. Within the Picker Institute Europe's report[2] the Trent Perinatal Network had the highest response rate (46%, n = 242) with the lowest response rate in South West Midlands Maternity & New born Network (31%, n = 346).

NNNI coverage was lower than that observed during the pilot study[3] (66% versus 31%) and this issue requires further investigation. This figure suggests that some NNUs may have limited the RDQ distribution to parents of infants who were being discharged home. Therefore, discharges to postnatal wards or other NNUs may have been missed. When the infant demographics (gestational age) for returned RDQs are compared to regional proportions for live discharges during 2012[4] the percentage of term infants is lower than expected in the sample of returned RDQs. In addition, RDQ returns where the length of stay was less than one day or between one day and one week also appear to be under-represented. Some NNUs informed the group that initially they found it difficult to establish a routine for RDQ distribution and collection. However, all NNUs subsequently reported that they had a routine established by the end of the year. During the pilot study an overall response rate of 80% was achieved and we are confident that if coverage can be improved and maintained during 2015/16 then we should once again meet this target.

Highlights

- The findings from the RDQ have demonstrated the quality of care and neonatal service provided throughout the NNNI. Overall, parental experience was rated at 98% for those respondents who had an infant discharged from neonatal care during the time period 1st April 2014 to 31st March 2015.

- Table 9, page 34 benchmarks NNNI RDQ results against comparable results of the Picker Institute Europe's parents' experiences of neonatal care survey.[2] NNNI has demonstrated a consistently higher performance across all equivalent quality indicators. However, it is important to note that the timing of survey completion may have influenced findings (i.e. NNNI RDQ completed close to discharge as opposed to after discharge home). To explore this issue we plan to analyse pilot data from one Health & Social Care Trust where two different parent questionnaires were running during the same time period with similar key questions. One was completed before discharge and one post-discharge. This will allow us to explore whether perceived satisfaction shifts according to timing of survey completion.

- Following reporting the RDQ findings to the PEG on 18th May 2015 there was further discussion regarding the best time to administer the RDQ. The majority of NNUs were happiest with completing just before discharge because of the risk of loss of feedback and the financial resources associated with the provision of return stamped, addressed envelopes for completion post-discharge. It was agreed that the RDQ would continue to be completed prior to discharge (with the postal option available following a quick discharge or transfer).

- Opportunities for further improvement have been identified at both network and individual NNU level. **Four priority areas** have been identified for action. These shared learning opportunities (defined by a response score of < 90% 'Yes, definitely' for any RDQ question) are detailed below:

1. Provision of information about help you could get with travelling expenses, parking costs or food vouchers.
   NNNI: 61%.
2. Provision of full explanations about the equipment surrounding baby. **NNNI: 87%.**
3. Provision of comfortable overnight accommodation.
   NNNI: 86%.
4. Promotion of **Skin-to-Skin** (kangaroo) care.
   NNNI: 87%.

- Data analysis demonstrated that the parents were happy to complete all questions with good level of completeness reported.

- Neonatal staff and parent feedback templates have been developed and will be piloted over the next six-months to (Appendix Three & Four). These will be placed in relevant social areas for staff and parents to promote the RDQ and to provide timely, quarterly, summary feedback which is unbiased and easy to understand. This will include any changes which have been implemented in response to parental feedback.

Strengths

- The NNNI RDQ has been designed in accordance with the validated 2010/11 parents' experiences of neonatal care survey from the Picker Institute Europe[5], as recommended by the National Institute of Clinical Excellence.[6] This facilitates national benchmarking. In addition, the RDQ Task and Finish group provided further input thereby giving the tailored RDQ local ownership.

- The NNNI RDQ was piloted and revised based on feedback from neonatal unit staff, TinyLife and experts in the area.[3]

- The co-ordinated approach of quarterly, feedback to each NNU ensures that NNU ward managers can discuss findings at relevant Health & Social Care Trust Committees.

- The multidisciplinary parental engagement group will be used as a means for timely dissemination to parents such as making the findings available on the TinyLife website.

Weaknesses

- RDQ coverage, although comparable to national figures, could be improved to a level similar to that attained during the pilot phase. Some parent groups were under-represented in the analyses particularly where the infant remained on the unit for a short time period.

- There were some delays in the initiation of data collection in some units which may have impacted negatively on coverage.

- Timing of completion of the RDQ may have inflated perceived performance due to a number of compounding factors such as insufficient time for parents to reflect on experiences at an already busy time just before discharge. As discussed previously these issues will be explored further by the PEG.

Recommendations

- Positive responses to the RDQ by parents, health professionals and academics indicate that the RDQ data collection, analyses and reporting should be integrated into NNNI activities on a routine basis as part of the ongoing monitoring of neonatal outcomes.

- RDQ quarterly feedback provision to NNUs using the agreed templates (Appendix Three).

- Inclusion of a parent representative on the Parent Engagement Group.

- Provision of RDQ parental feedback using agreed templates (Appendix Four).

- Consideration should be given to an Annual NNNI shared learning workshop to promote good practice using RDQ findings.

- Consideration should be given to RDQ translation into the three most common international languages.

- Consideration should be given to the development of an RDQ supplemental post-discharge survey focusing on the transition home and family post-discharge support.

Section 1: Background & Method

1.1 Introduction

In NI, provision of neonatal services is shared by five Health and Social Care Trusts (HSCTs): Belfast, South Eastern, Northern, Southern and Western. There are currently seven neonatal facilities: one regional unit providing specialised services (Royal Maternity Hospital (RMH), four area units providing continuing IC/HDC (Ulster (ULST), Antrim (ANT), Craigavon (CAH), Altnagelvin (ALT) and two smaller units, Daisy Hill (DH) and South West Acute Hospital (SWAH), providing short-term IC/HDC (Figure 1). The current complement of cot levels, as defined by the British Association of Perinatal Medicine (BAPM)[7] for the region is: 21 level 1 (Intensive Care (IC)), 21.25 level 2 (High Dependency Care (HDC)) and 63.75 level 3 (Special Care (SC)) (Figure 2). In addition, the Royal Belfast Hospital for Sick Children (RBHSC), located in Belfast, provides surgical and specialist medical care. Infants are primarily transferred between NNUs according to clinical need. Each year there are approximately 25,000 infants born alive in Northern Ireland with one in 14 infants admitted to a neonatal unit for specialist care; with one in 20 requiring IC and/or HDC.[4]

The specialist neonatal care quality standard produced in 2010 by the National Institute of Clinical Excellence[3] states:

> *Parents of babies receiving specialist neonatal care can expect to be encouraged and supported to be actively involved in planning and providing care, joint decision-making and to be in regular contact with their healthcare team. (NICE, 2010, p. 17)*

It is therefore important to continually monitor the performance of healthcare teams against this quality standard. Assessing the quality of care provided is not a new concept. In 1988, Donabedian[8] explained that there are two aspects to the performance of heath care teams namely: technical and the interpersonal relationship. The latter is vitally important as it facilitates the implementation of the

technical care. Patient (or in this case parental) satisfaction is a desired outcome of care and an indicator of perceived quality. Donabedian defines the articulation of satisfaction or dissatisfaction as the patient (or parents') judgement on the quality of all aspects of care particularly the interpersonal process.[8] Seeking the views and experiences of parents and families provides a wealth of information for neonatal staff through both the identification of good practice and by highlighting areas for further improvement. This allows healthcare providers to tailor services to the needs of parents and families which is fundamental to a family-centred care approach. A recent integrative review[9] of parent satisfaction with care provided in the neonatal intensive care unit concluded that the majority of parents are highly satisfied with the care received. However, there is also evidence of less than optimal care which does not meet parents' expectations.[9]

The following key areas were highlighted as contributing positively to parental satisfaction:

- Involvement in the infant's care giving;
- Nurse- to-parent support;
- Communication and unbiased information exchange;
- Staff behaviours and attitudes with respect to encouragement of parenting skills and empowerment of parents and
- Recognition that the infant belongs to the parents and fostering a caregiving partnership.[9]

This is the first report of the Parent Engagement Group of the Neonatal Network Northern Ireland (NNNI). The Regional Discharge Questionnaire (RDQ) is designed to capture parents' experiences of neonatal care throughout Northern Ireland. This report aims to provide a comprehensive analysis of the RDQ at both regional and unit level. The information presented pertains to parents of infants discharged from any neonatal unit (NNU) during the time period 1st April 2014 to 31st March 2015.

Figure 1: Location of neonatal units in NNNI

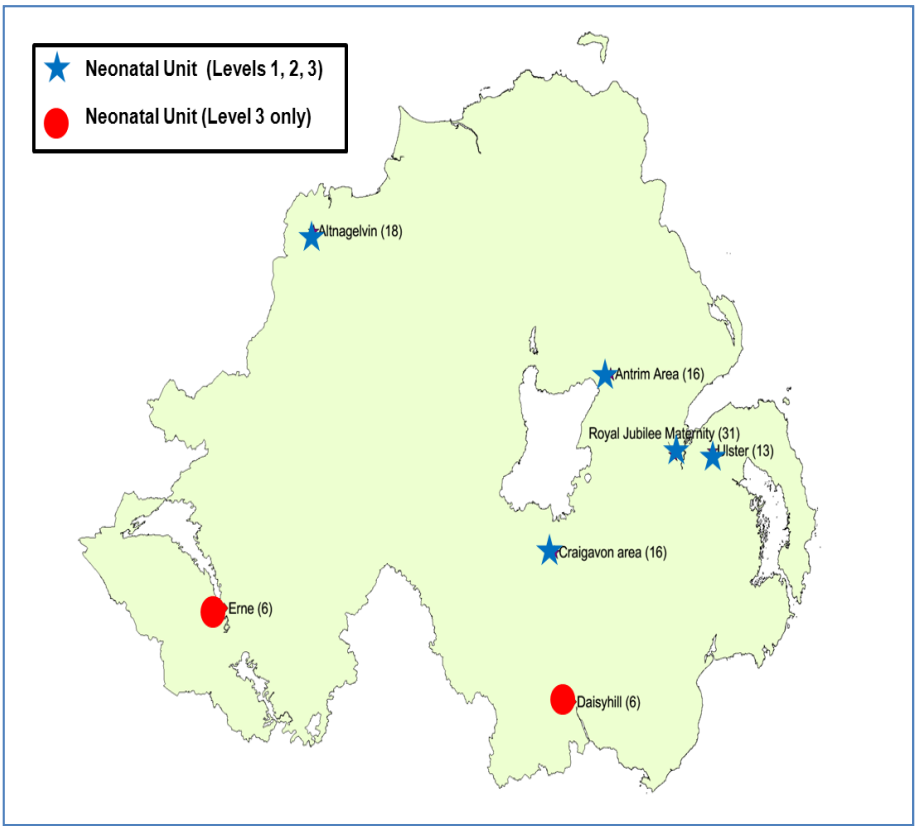


Figure 2: Neonatal Cot Complement for NNNI.

NNU	Level 1 cots (ICU)	Level 2 Cots (HDU)	Level 3 cots (SC)	Total
ALT**	3	6	9	18
ANT**	4	2	10	16
CAH**	3	4	9	16
DH*	0	0.25	5.75	6
SWA*	0	0	6	6
RMH***	9	7	15	31
ULST**	2	2	9	13
Total	21	21.25	63.75	106

***Regional Unit provides neonatal care across all levels in addition to tertiary services, ** Area units provide neonatal intensive care, high dependency care and special care, *Provide special care only (Daisy Hill has one cot part-funded for level 2)

1.2 Method

The pilot RDQ was revised by the multidisciplinary Regional Discharge Questionnaire (RDQ) Task and Finish Group[3] which preceded the Parental Engagement Group (PEG) (Appendix One). Implementation was carried out by the existing QUB team[3] as follows:

- **All parents** whose babies received neonatal care and were discharged from any NNU within the NNNI were invited to complete an RDQ. Parents of babies who died were excluded as the RDQ Task and Finish Group agreed that a specific questionnaire should be developed for this group of bereaved parents.

- Parents were asked to complete the RDQ just **before discharge** and completed questionnaires were **left in a closed box** in the parents' room or another location convenient for parents. This ensured confidentiality in order to foster a true reflection of the care provided.

- Regular contact was maintained with each NNU and RDQs were collected in person every week/two weeks.

- Data were processed and analysed centrally in the School of Nursing & Midwifery, Queen's University Belfast (QUB) using the Predictive Analysis Software, PASW® Statistics 18 (SPSS Inc, Chicago, Illinois, USA).[11]

- Denominator data (number of discharges) during the study time period were provided by neonatal staff.[1]

Section 2: Results

2.1 Coverage and response rate

During the study time period (1st April 2014 to 31st March 2015) 1974 live infants were discharged from NNUs in NI. Across the region coverage (number of questionnaires returned as a percentage of the number of live discharges during the study time period) ranged from 18.9 % to 42.4%, with an overall regional coverage of 31.2%. This suggests that some NNUs may have limited distribution of the RDQs to parents of infants who were being discharged home. Therefore, discharges to postnatal ward or other NNUs may have been missed. Table 1 provides a breakdown of coverage by NNU.

Table 1: Number of discharges and coverage by NNU

Neonatal Unit	#Discharges	Coverage (%)
Altnagelvin	286	110 (38.5%)
South West Acute	118	50 (42.4%)
Craigavon	334	105 (31.4%)
Daisy Hill	163	53 (32.5%)
Antrim	286	100 (40.0%)
Ulster	292	104 (35.6%)
Royal Maternity	495	93 (18.8%)
Regional Total	**1974**	**615 (31.2%)**

 # Deaths during the neonatal stay have been excluded.

The recent 2014 report on parents' experiences of neonatal care from the Picker Institute Europe[2] has reported an overall response rate of 37.6% received from a sample of 6000 parents. This is comparable to the NNNI coverage (proxy for response rate) of 31.2%, although this may be under-estimated due to some difficulties with distribution. Within the Picker report Trent Perinatal Network received the highest response rate (46%, n = 242) and the lowest response rate was achieved in South West Midlands Maternity and Newborn Network (31%, n = 346). Our

coverage was lower than that observed during our pilot study (66% versus 31%).[3] During the pilot study we achieved a response rate of 80% and we are confident that if high coverage can be achieved and maintained then we should once again meet this target. The findings from the pilot study suggest that parents' within the NNNI are more than happy to complete the RDQ and that coverage this year was lower than expected and this issue requires further investigation.

In order to ascertain the cause of this low coverage we investigated by obtaining feedback from NNU representatives and by using our most up to date demographic data for all infants discharged from NNUs.

Some issues raised by staff included the length of time to establish a system for RDQ distribution within units resulting in missed transfers at night and missed short stays particularly when the infant is transferred back to the postnatal ward.

When the infant demographics (gestational age) for returned RDQs are compared to regional proportions for live discharges during 2012; it would appear that term infants are under-represented in the sample of returned RDQs given that a proportion of 43% would have been expected (Table 2a). In addition, RDQ returns where the length of stay was less than one day also appear to be under-represented. (Table 2b).

Table 2a: Sample proportions (al live discharges) by gestational age

*Gestational age group (completed weeks)	#Live Discharges	Returned RDQs NNNI (Network)
less than 28	118 (5.5%)	4.4%
28 to 30	161 (7.5%)	11.0%
31 to 33	382 (17.9%)	19.5%
34 to 36	559 (26.2%)	28.7%
Term (37 or more)	**913 (42.8%)**	**36.3%**
No response	-	6 Cases
	2133	**615**

#2012 available. *Wording of question flawed: changed in RDQ15/16 (Appendix Two)

Table 2b: Sample proportions (al live discharges) by Length of Stay

*Length of stay	#Live discharges	Returned RDQs NNNI (Network)
Less than 1 day	**133(6.2%)**	**1.3%**
Between one day and one week	968(45.4%)	35.1%
Between 1 week and 8 weeks	950 (44.5%)	55.7%
More than 8 weeks	82(3.8%)	7.9%
No response	**-**	**8 cases**
	2133	**615**

#2012 available. *Wording of question flawed: changed in RDQ15/16 (Appendix Two)

2.2 Respondent (parent/guardian) demographics

The majority of RDQs were completed by the mother 69.9% (422/604), fathers completed 19.7% (119/604) and 5.6% (34/604) of RDQs were completed jointly (mother and father). Other responses 4.8% (29/604) included 'foster mother', 'parent', 'parents', 'Poland', 'son' and 'special and precious.' Information was unavailable in 11 cases.

2.2.1 Respondent age groups

The majority of respondents 98.7% (595/603) were 18 years of age or more with 16.3% (98/603) between the ages of 18 and 24, 24.0% (145/603) were 25 to 29 years, 30.8% (186/603) were 30 to 34 years and 21.6% (130/603) were 35 to 39 years. Six percent of mothers (36/603) were 40 years or over. Information was unavailable in 12 cases.

2.2.2 Respondent residence

The majority of respondents 71.5% (432/604) lived in a town/city and the remaining 28.5% (172/604) in a country area at the time of the study. Information was unavailable in 11 cases.

2.2.3 Respondent journey time to NNU

Journey time from home to NNU was within one and a half hours for most respondents, with 60.5% (367/607) taking less than 30 minutes, 30.5% (185/607) between 30 and 59 minutes and 7.4% (45/607) taking between one and one and a half hours. Ten respondents' (1.7%) journey time took over one and half hours. Information was unavailable in eight cases. Table 3 provides a breakdown of journey times by NNU.

Table 3: Journey time (home to NNU) split by NNU

Journey time (mins) / Neonatal Unit	Less than 30	30 to 59	60 to 90	90 to 120	Over 120
Altnagelvin	57	32	13	4	3
South West Acute	29	16	4	0	0
Craigavon	60	39	6	0	0
Daisy Hill	40	13	0	0	0
Antrim	47	39	10	1	0
Ulster	67	30	5	1	0
Royal Maternity	67	16	7	1	0
Regional Total	**367**	**185**	**45**	**7**	**3**

2.2.4 Respondent marital status

Overall, 81.1% (482/594) of respondents were married or co-habiting at the time of the study with 16.3% (97/594) either single, separated or divorced. Fifteen respondents (2.5%) were categorised as 'other' and described themselves as: having a 'partner' or 'boyfriend', being 'engaged' or in a 'relationship'. Information was unavailable in 21 cases.

2.2.5 Respondent employment status

Over half of the respondents 57.4% (342/596) were in full-time employment, 13.3% (79/596) were employed part-time, almost a quarter 24.8% (148/596) were unemployed and 4.5% (27/596) were in education (students). Information was unavailable in 19 cases.

Where reported, 73.8% (403/546) of respondents' partners were in full-time employment, 8.2% (45/546) were employed part-time, 15% (82/546) were unemployed and 2.9% (16/546) were in education. Information was unavailable in 69 cases (marital status: single (41), co-habiting (4) Married (11), Divorced (1), other (2) and missing (10)).

2.2.6 Respondent ethnic or other minority group

The majority 94.4% (535/567) of respondents did not consider themselves to belong to an ethnic or other minority group. Information was unavailable in 48 cases.
Thirty-two respondents reported minority groups as follows: Asian (1), Black African (1), Black British (1), Catholic (2), Greek (1), Hungarian (1), Indian (2), Irish traveller (2), Malaysian (1), Persian (1), Timorence (1), White (5), White British (3), White Irish (1). This suggests that perhaps this question could be revised in line with recent census categorisations of nationality.

2.2.7 Respondent disability or special need

The majority 97.8% (589/602) of respondents did not consider themselves to have a disability or special need. Information was unavailable in 13 cases. Nine of 544 respondents (1.7%) considered their partner to have a disability or special need. Information was unavailable in 71 cases.

2.2.8 Respondent other children

Just over half 54.8% (331/604) of respondents reported having other children, ranging from one child (52.7%) to six children (1.2%). Information was unavailable in

11 cases. The median number of children was one child and the most frequent (mode) was one child. Information was unavailable for six cases.

2.3 Infant details

2.3.1 Gestational age at birth (completed weeks)

Most infants, 36.3% (221/609) were term (more than 37 weeks' gestation), 28.7% (175/609) were late preterm (34 to 36 weeks' gestation), 19.5% (119/609) were 31 to 33 weeks' gestation, 11.0% (67/609) were 28 to 30 weeks' gestation and 4.4% (27/609) were extremely preterm (less than 28 weeks' gestation). Information was unavailable in six cases. Table 4 provides a regional overview of infant gestational age at birth and for individual NNUs.

Table 4: Gestational age (completed weeks) at birth split by NNU

Gestational age group (completed weeks) / Neonatal Unit	< 28	28 to 30	31 to 33	34 to 36	> 37
Altnagelvin	4	12	19	33	39
South West Acute	2	2	6	20	19
Craigavon	6	18	27	32	21
Daisy Hill	0	5	9	14	25
Antrim	6	12	19	31	32
Ulster	4	13	24	21	42
Royal Maternity	5	5	15	24	43
Regional Total	**27**	**67**	**119**	**221**	**609**

Note: information unavailable in six cases.

2.3.2 Length of stay in discharging NNU

Over half of infants, 55.7% (338/607) remained in the NNU for one to eight weeks, while 35.1% (213/607) had a length of stay between one day and one week, with 48

infants (7.9%) remaining on the neonatal unit for more than eight weeks. Only eight infants (1.3%) included in the survey remained on the NNU for less than one day. Information was unavailable in eight cases.

As previously reported during the pilot study, this suggests that parents of infants discharged to the postnatal ward or to another neonatal unit/ Royal Belfast Hospital for Sick Children (RBHSC) within one day may not have received an RDQ. Table 5 provides a breakdown of length of stay by NNU.

Table 5: Length of stay split by NNU

Length of stay / Neonatal Unit	< 1 day	1 day to 1 week	1 to 8 weeks	> 8 weeks
Altnagelvin	3	54	38	13
South West Acute	0	19	30	0
Craigavon	1	27	62	13
Daisy Hill	0	24	27	1
Antrim	4	29	59	8
Ulster	0	35	62	6
Royal Maternity	0	25	60	7
Regional Total	**8**	**213**	**338**	**48**

Note: Information unavailable in eight cases.

2.3.3 Source of admission (transfer into NNU from another NNU)

One hundred and eight respondents indicated that there was a transfer associated with this admission to NNU. In 98 cases (88.3%) the staff clearly explained why the baby was being transferred to a different hospital and in ten cases (9%) the reason was explained to some extent. In three cases (2.7%) staff did not clearly explain why the infant was being transferred to a different unit.

This question is open to mis-interpretation and has caused some confusion regarding transfers in and out on the NNU. Therefore, as highlighted in the previous

pilot report this question has been re-worded and re-structured in the current version of the RDQ.

2.3.4 Previous admissions to NNUs

One hundred respondents indicated that their infant had been transferred in from a previous NNU. Table 6 represents the reported transfer pattern from the sending to the receiving neonatal unit.

Table 6: Transfer patterns - sending NNU and receiving NNU.

Sending NNU

Receiving NNU

	ALT	SWAH	CAH	DHH	ANT	ULST	RMH	Coding error	Total
ALT	0	3	2	0	1	0	6	0	12
SWAH	1	0	1	2	1	0	5	0	10
CAH	0	0	2	1	2	1	12	0	18
DHH	0	0	13	1	1	0	2	0	17
ANT	1	0	1	0	0	0	15	2	19
ULST	2	0	1	1	0	0	12	0	16
RMH	0	1	4	0	0	3	0	0	8
Total	4	4	24	5	5	4	52	2	100

ALT (Altnagelvin), SWAH (South West Acute Hospital), CAH (Craigavon), DHH (Daisy Hill), ANT (Antrim), ULST (Ulster), RMH (Royal Maternity).

This question has been re-structured in the current version of the RDQ. As demonstrated above responders may not have been clear on what constitutes a 'transfer in'. In addition, Royal Belfast Hospital for Sick Children needs to be added into the list since some infants may be re-admitted to the same NNU after surgery.

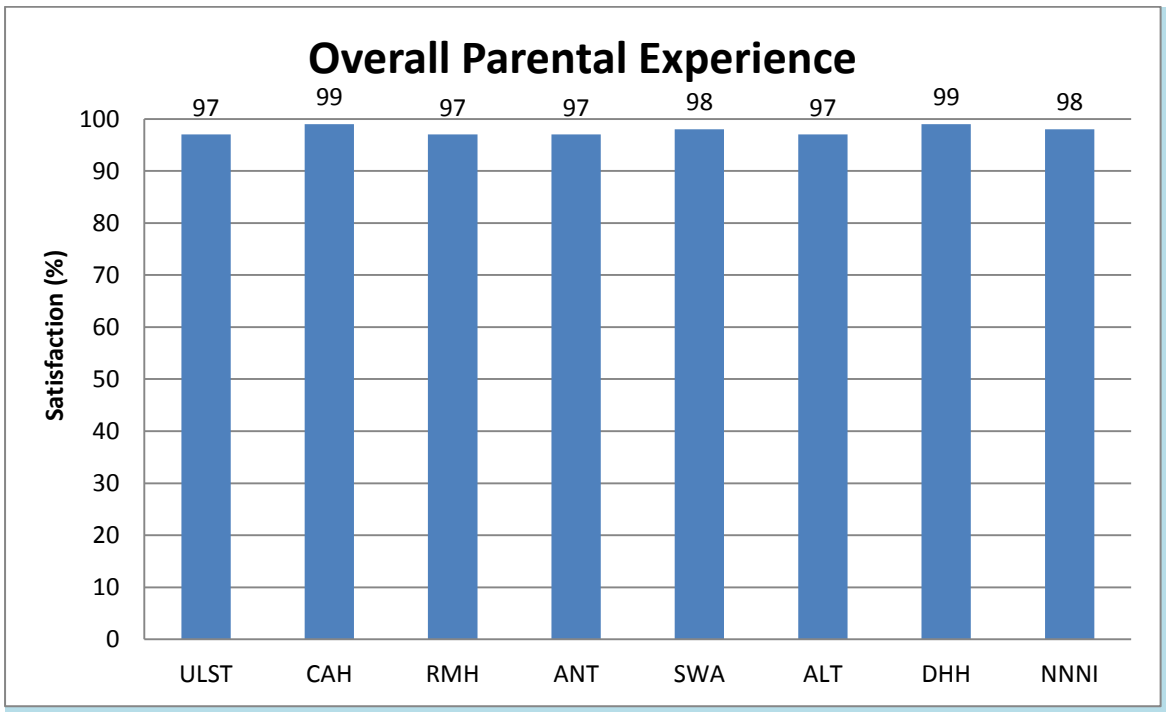
2.4 Overall Satisfaction

RDQ question 29:
On a scale of one to ten, where one is very poor and ten is excellent, how would you rate your experience in our neonatal unit?

99.8% respondents rated their neonatal care experience as 7 or more, with 83.8% (511/610) giving a score of 10, 11.5% (70/610) giving a score of 9, 3.8% (23/610) giving a score of 8 and 0.8% (5/610) giving a score of 7. Only one respondent (0.2%) gave a score of 5. Overall, NNUs had a mean score (SD) of 9.78 (0.58) and a median score of 10. Five respondents declined to provide an overall performance score.

Overall, NNNI neonatal units scored 5964 points out of a possible 6100 (97.8%) for satisfaction with neonatal experience.

Figure 3:



Note: Information was unavailable for five cases.

2.5 About baby's Care: Overview of Regional findings

Table 7a and 7b provide an overview of regional findings pertaining to the care provided on NNUs in NNNI covering RDQ questions 6 to19 and questions 20 to 27 respectively.

Table 7a: About baby's Care

RDQ Question	Yes definitely	Yes, to some extent	No	Unsure/ forgotten	No Response (M)/ Not Applicable (NA)
6. When you visited the unit, did staff caring for your baby introduce themselves to you?	594/611 (97.2%)	17/611 (2.8%)	0/611 (0%)	0/611 (0%)	4M
7. When you first visited the unit, did staff show you how to wash your hands using the 7-step technique?	560/613 (91.4%)	33/613 (5.4%)	16/613 (2.6%)	4/613 (0.7%)	2M
8. Did a member of neonatal staff talk to you about your baby's condition and treatment after the birth?	572/610 (93.8%)	31/610 (5.1%)	3/610 (0.5%)	4/610 (0.7%)	5M
9. When you first visited your baby, were you given enough information about the neonatal unit?	561/611 (91.8%)	42/611 (6.9%)	7/611 (1.1%)	1/611 (0.2%)	4M
10. Were you given information about help you could get with travelling expenses, parking costs or food vouchers?	363/598 (60.7%)	98/598 (16.4%)	127/598 (21.2%)	10/598 (1.7%)	17M
11. Was the equipment surrounding your baby explained fully to you?	533/611 (87.2%)	63/611 (10.3%)	12/611 (2.0%)	3/611 (0.5%)	4M
12. Did you feel you were able to talk to staff on the unit about your worries and concerns?	578/611 (94.6%)	32/611 (5.2%)	1/611 (0.2%)	0/611 (0%)	4M
13. Were health professionals on the neonatal unit sensitive to your emotions and feelings?	572/610 (93.8%)	34/610 (5.6%)	2/610 (0.3%)	2/610 (0.3%)	5M
14. Did staff keep you up to date with your baby's condition and progress?	580/611 (94.9%)	28/611 (4.6%)	1/611 (0.2%)	2/611 (0.3%)	4M
15. In your opinion, was important information about your baby passed from one member of staff to another?	557/608 (91.6%)	39/608 (6.4%)	3/608 (0.5%)	9/608 (1.5%)	7M
16. When you asked questions about your baby's condition and treatment, did you get answers you could understand?	566/610 (92.8%)	41/610 (6.7%)	3/610 (0.5%)	0/610 (0%)	5M
17. If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you comfortable accommodation?	478/554 (86.3%)	41/554 (7.4%)	25/554 (4.5%)	10/554 (1.8%)	28M 33 NA
18. Were you able to contact the neonatal unit by telephone whenever you needed to?	592/605 (97.9%)	9/605 (1.5%)	2/605 (0.3%)	2/605 (0.3%)	10M
19. While you were there, did staff wash their hands or use hand gel before touching your baby? ★	606/610 (99.3%)	4/610 (0.7%)	0/610 (0%)	0/610 (0%)	5M

*** In one case 'husband was show but not me as visited unit at different times.'**

Table 7b: About Baby's Care

RDQ Question	Yes definitely	Yes, to some extent	No	Unsure/ forgotten	Not Applicable	No response
20. If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?	421/431 (97.7%)	9/431 (2.1%)	0/431 (0%)	1/431 (0.2%)	163	21
21. If you wanted to breast feed your baby, were you given enough support from the neonatal unit staff to do this?	344/364 (94.5%)	20/364 (5.5%)	0/364 (0%)	0/364 (0%)	236	15
22. Were you happy with breastfeeding facilities within your unit?	351/372 (94.4%)	18/372 (4.8%)	3/372 (0.8%)	0/372 (0%)	217	26
23. If you wanted to bottle feed your baby were you given enough support from the neonatal unit staff to do this?	486/508 (95.7%)	20/508 (3.9%)	2/508 (0.4%)	0/508 (0%)	84	23
24. Were you or your partner or companion involved in the day-to-day care of your baby?						
Nappy changing?	572/610 (93.8%)	34/610 (5.6%)	4/610 (0.7%)			5
Feeding?	568/608 (93.4%)	33/608 (5.4%)	7/608 (1.2%)			7
Skin-to-skin contact/kangaroo care?	**497/570 (87.2%)**	**43/570 (7.5%)**	**30/570 (5.3%)**			**45**
25. Overall, did staff help you feel confident in caring for your baby?	595/612 (97.2%)	17/612 (2.8%)	0/612 (0%)	0/612 (0%)		3
26. Did you feel prepared for your baby's discharge from the neonatal unit?	568/605 (93.9%)	34/605 (5.6%)	3/605 (0.5%)	0/605 (0%)		10
27. Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?	556/599 (92.8%)	25/599 (4.2%)	11/599 (1.8%)	7/599 (1.2%)		16

2.5.1 Day-to-day care of your baby

RDQ question 24: 'Other activities' were indicated in nine cases, namely: 'Abidec medicine', baby went straight into incubator', 'bath/washing (3), 'bathing and dressing (2)', bathing/medicines for discharge.'

2.6 Aspects for improvement

RDQ question 28: Overall, respondents indicated that the following aspects of the NNU could be improved: light level 2.4% (15/615), noise level 2.4% (15/615), cleanliness 0.3% (2/615), temperature 6.5% (40/615) and baby's comfort 1.0% (6/615).

2.7 Overall Comments: Key opportunities for improvement

Two hundred and seventy-two (44.2%) respondents commented on their neonatal care experiences. The majority, 87.9% (239/272) were positive in nature, 3.7% (10/272) described mixed experiences and 8.5% (23/272) expressed concern or described opportunities for improvement (Table 8).

Table 8: Key opportunities for improvement

Comment Category	Frequency	Percent %
Facilities or comfort	15	45.5
Staff support	1	3.0
Feeding	3	9.1
General	1	3.0
Communication	3	9.1
Information	3	9.1
Visiting	4	12.1
Standardisation	2	6.1
Multiple domains	1	3.0
Total	**33**	**100.0**

2.7.1 Facilities or comfort

- "More express rooms, parent rooms need to be more friendly and pleasant to use i.e. not a store."
- "When staying in parents' room the bedding could be improved. Staff apologised for and seemed a bit embarrassed as was only a sheet (thin) and not very comfy."
- "Light level at night."
- "Temperature - some areas are very draughty - air conditioning."
- "Accommodation facilities not easily available due to renovation work."
- "Too many beeps."
- "I think the Unit would benefit from an on-site counsellor to help deal with trauma and anxiety of having a sick/prem baby."

- “Very hot weather 30 whilst in Unit and air conditioning would have been beneficial.”
- “My baby was 14 weeks old when he was discharged and for some weeks should have been in a bigger cot which wasn't available as the neonatal unit have only small cots.”
- “Bins need softer closing.”
- “Excellent care, just sometimes rooms were too hot or too cold. ICU space seemed cramped, concerned it was difficult for staff to do their job.”
- “Bins in unit close loudly/loud radio at times.”
- “It can be a little hot.”
- “Quite hot.”
- “……the unit was slightly noisy form time to time but it is understandable…(machines beeping).”

2.7.2 Staff Support

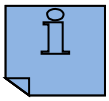
- “We felt staff lacked the people skills needed to support parents – little to no empathy shown.”

2.7.3 Infant Feeding

- “I felt that I wanted to introduce bottles to feed breast milk, that I was not supported and was left feeling that I was making a poor/bad choice.”
- “Feeding was mainly done while we were at home. Staff seemed to genuinely care for my baby in my absence.”
- “Neonatal facilities were excellent. However, it was very stressful for mother who is breastfeeding regularly to be on a separate ward down the corridor. Gives no rest for mother to recover and encourages mother to switch to bottle feeding.”

2.7.4 Communication

- "Some inconsistencies in advice given, different answers from different people, important information not always passed from member of staff to another."
- "The only negative I experienced was by Staff Nurse XXX. She questioned whether I thought my partner and I needed he help as we both claimed we were tired in general conversation. She asked this in an inappropriate way – in front of other visitors while my partner was away."
- "At times methods of oral communication to parents could have been better co-ordinated in order to improve clarity."



2.7.5 Information

- "Whilst he was in ICU we were unclear whether he was actually ICU classed, perhaps reassurance can be given if baby is in ICU but not classed ICU."
- "We were not told she that there was a possibility that she could get moved to Dundonald because of our postcode and will have difficulty getting there as my husband works away at the weekends and I have a C-Section and can't drive for six weeks and am trying to feed her myself. Also I have two young children at home that need taken to and from school."
- "Somethings were not explained to me at the start. Like that we were not allowed to pick up the baby's notes. I was pulled by one of the nurses about in in not a nice manner…"

2.7.6 Visiting

- “I believe if a baby is well enough grandparents should be allowed to touch and cuddly baby as they are already in close contact during visiting times and they have followed infection control measures on entering Unit……..”
- “Grandparents and siblings should be allowed to visit at certain times.”
- “The possibility of other family members to visit i.e. sisters and brothers.”

2.7.7 Standardisation

- “Consistency of methods needed for all members of staff.”
- “Nappy changes could be more frequent than ever 3 hours.”

2.7.8 Other

- “……However, I do feel better provisions could be put in place for disabled mothers and also some inconsistency with different nurses in terms of things that you are told.”
- “I did not find ICU a great experience but once they were moved I felt better about visiting and found the staff very helpful.”

2.8 Overall comments: positive experiences

Each NNU will be provided with full comments recorded for their unit. However, some examples of positive experiences from each NNU across NI are as follows:

2.8.1 Altnagelvin Area Hospital, Neonatal Unit

- "Our baby received the best care possible while staying in the NICU. We cannot praise the wonderful staff high enough for the care, respect and love they have shown to our baby while in their care. Fantastic nurses and doctors."
- "I felt like all the staff were great especially XXXX and XXXX. They went over and above what I expected of them. They gave us excellent support all through our time in the Unit. Great Team."
- "The staff in the NICU were amazing. Every single one of them made me feel like we were a priority. Very friendly, understanding and patient. They didn't mind explaining things (sometimes repeatedly). Very caring. Other than that for the reason for our needing their services (sick baby), I can't say we had a single negative experience. World class."
- "Thank you to everyone in the Unit who were involved in the care of our baby. Everyone was helpful and provided all the information we required. Each and everyone working in the Unit are a credit to the Health Service. Thank you so much."
- "The care my baby received was 100%."

2.8.2 South West Acute Hospital, Special Care Baby Unit

- "The staff in the Neonatal Unit were absolutely fantastic to me and my family. I feel we are very lucky to have such an excellent service in the Trust."
- "The care our son received was fantastic. All the girls were very good to deal with and talk too and we couldn't ask for more."
- "My twins boys were in the Neonatal Unit for almost three weeks and they could not have received better care. The neonatal team in the SWA were

fantastic, always giving great care to the boys and reassuring myself and my husband."

- "All staff were so professional, understanding, informative and caring. Offered support and advice throughout stay. Amazing care."
- "I have to say staff were brilliant with my son and made me feel very comfortable and relaxed and confident for him coming home.

2.8.3 Craigavon Area Hospital, Neonatal Unit

- "XXXX was a twin and our first babies and even though she was separated from her sister the people in neonatal made it as easy for us as possible to see each twin separately as we knew XXXX was in the best possible place."
- "All staff were fantastic. The care we received has been outstanding and we cannot speak highly enough of all staff."
- "The staff in the neonatal were absolutely amazing. Their level of care and support to our baby, as well as our selves was simply brilliant. I cannot praise them enough."
- "All care was fantastic, thank you."
- "The level of care, attention and support from all the staff was excellent. Staff are warm, friendly and always approachable. Information exchange between staff regarding our baby was observed to be excellent. At all times our impression was of a committed hard working dedicated multi-disciplinary team whose aim was to provide the highest standard of care to babies in the NNU."

2.8.4 Daisy Hill Hospital, Special Care Baby Unit

- "The nurses in both Craigavon and Daisy Hill were exceptional in the care for our baby during his nine weeks in their care. A credit to XXXX and XXXX."
- "Excellent staff. Assured to know baby was in the best possible care."
- "We have had a great experience in the SCBU with my son XXXX. All staff gave us lots of support and guidance regarding my son. I feel I was offered great support regarding breastfeeding. First class experience."

- "We cannot fault SCBU at DHH. the staff are amazing and they looked after our wee man in a caring and professional manner. 100% respect."
- "Very happy with the service and care for my baby."

2.8.5 Antrim Area Hospital, Neonatal Unit

- "The team dealt really well with our son's condition given that it is a rare condition and not much known about it."
- "When pregnant the thought of my babies going into neonatal care was scary, but all staff have been amazing and any baby that has to go into neonatal is in very good hands. Excellent care for babies and excellent support for parents."
- "Staff more than helpful. All very friendly. Our son was looked after very well and we were always well informed of his progress."
- "Everyone who looked after us was very professional and helpful. They did a fantastic job and easy to talk to."
- "We were very satisfied with staff and care of our baby in the neonatal unit. They helped us a lot and they were very nice, pleasant staff which always helped out whatever we needed and answered all questions."

2.8.6 Ulster Hospital, Neonatal Unit

- "Absolutely amazing people doing an amazing job. They don't just look after the baby, they look after the parents too! "
- "Nurses were very patient when teaching us and helping us achieve all competencies. We felt that our opinions were taken on board at all times."
- "The staff in the Ulster Neonatal Unit were fantastic from my son arrived until he was discharged. They made me feel at ease and understand what was happening and were fantastic at their job. I cannot even describe how much they cared for my son, much appreciated."
- "……In a very fluid situation, we were kept informed and up-to-date with all aspects of care……"

- “……..You are like family to us and we will be back up visiting no doubt.”

2.8.7 Royal Maternity Hospital, Neonatal Unit

- “The staff here have been very professional and caring towards our baby and us as parents. They have provided a helping hand for us during this difficult time which has been invaluable and never forgotten.”
- “I found every aspect of the care given to my daughter to be excellent. All staff were friendly and approachable, the doctors, nurses, auxiliary and cleaning staff and receptionists in NICU. I couldn’t find any fault and am very happy with the care given and the hygiene standards of the unit.”
- “Staff were all very helpful and friendly and kept us informed of baby's progress every day. The operation and diagnosis drawn and explained in a manner which we understood.”
- “In our experience the staff in the neonatal unit were consistently excellent, knowledgably informed and caring to both baby and parents.”
- “Our daughter was given the best possible care on a daily basis. We were delighted with the care and felt comfortable at night when going home that our baby was safe and looked after by staff.”

Section 3: Conclusions & Recommendations

3.1 Conclusions

3.1.1 Representativeness

During the study time period (1st April 2014 to 31st March 2015) 1974 live infants were discharged from neonatal units (NNUs) in Northern Ireland (NI).[1] Across the seven NNUs in NI coverage (number of questionnaires returned as a percentage of the number of live discharges during the study time period) ranged from 18.9% to 42.4%, with an overall NNNI coverage of 31.2%.

The recent 2014 Picker Institute Europe report on parents' experiences of neonatal care survey[2] (which took place during a similar time period involving 88 NNUs from 13 neonatal networks in England) stated an overall response rate of 37.6% for a sample of 6000 parents who completed the survey after discharge home.[2] This is comparable to the NNNI coverage (proxy for response rate) of 31.2%, although this may be under-estimated due to some difficulties with RDQ distribution. Within the Picker Institute Europe's report[2] the Trent Perinatal Network had the highest response rate (46%, n = 242) with the lowest response rate in South West Midlands Maternity & New born Network (31%, n = 346).

NNNI coverage was lower than that observed during the pilot study[3] (66% versus 31%) and this issue requires further investigation. This figure suggests that some NNUs may have limited the RDQ distribution to parents of infants who were being discharged home. Therefore, discharges to postnatal wards or other NNUs may have been missed. When the infant demographics (gestational age) for returned RDQs are compared to regional proportions for live discharges during 2012[4] the percentage of term infants is lower than expected in the sample of returned RDQs. In addition, RDQ returns where the length of stay was less than one day or between one day and one week also appear to be under-represented. Some NNUs informed the group that initially they found it difficult to establish a routine for RDQ distribution and collection. However, all NNUs subsequently reported that they had a routine

established by the end of the year. During the pilot study an overall response rate of 80% was achieved and we are confident that if coverage can be improved and maintained during 2015/16 then we should once again meet this target.

3.1.2 Highlights

- The findings from the RDQ have demonstrated the quality of care and neonatal service provided throughout the NNNI. Overall, parental experience was rated at 98% for those respondents who had an infant discharged from neonatal care during the time period 1st April 2014 to 31st March 2015.

- Table 9, page 34 benchmarks NNNI RDQ results against comparable results of the Picker Institute Europe's parents' experiences of neonatal care survey.[2] NNNI has demonstrated a consistently higher performance across all equivalent quality indicators. However, it is important to note that the timing of survey completion may have influenced findings (i.e. NNNI RDQ completed close to discharge as opposed to after discharge home). To explore this issue we plan to analyse pilot data from one Health & Social Care Trust where two different parent questionnaires were running during the same time period with similar key questions. One was completed before discharge and one post-discharge. This will allow us to explore whether perceived satisfaction shifts according to timing of survey completion.

- Following reporting the RDQ findings to the PEG on 18th May 2015 there was further discussion regarding the best time to administer the RDQ. The majority of NNUs were happiest with completing just before discharge because of the risk of loss of feedback and the financial resources associated with the provision of return stamped, addressed envelopes for completion post-discharge. It was agreed that the RDQ would continue to be completed prior to discharge (with the postal option available following a quick discharge or transfer).

- Opportunities for further improvement have been identified at both network and individual NNU level.

Four priority areas have been identified for action at Network level. These shared learning opportunities (defined by a response score of < 90% 'Yes, definitely' for any RDQ question) are detailed below:

1. Provision of information about help you could get with travelling expenses, parking costs or food vouchers.
   NNNI: 61%. ★ Best Practice NNU: Daisy Hill Hospital: 78.4%

2. Provision of full explanations about the equipment surrounding baby.
   NNNI: 87%. ★ Best Practice NNU: South West Acute Hospital: 95.9%

3. Provision of comfortable overnight accommodation.
   NNNI: 86%. ★ Best Practice NNU: Ulster Hospital: 95.0%

4. Promotion of **Skin-to-Skin** (kangaroo) care.
   NNNI: 87%. ★ Best Practice NNU: Craigavon Area Hospital: 91.0%

Nine priority areas have been identified for action at local NNU level. These shared learning opportunities (defined by a response score of < 90% 'Yes, definitely' for any RDQ question at individual NNU level) are detailed below:

1. When you first visited the unit, did staff show you how to wash your hands using The Seven-Step-Technique?

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

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

4. Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?

5. Were you and your partner or companion involved in the day to day care of your baby? (Nappy changing & Feeding)

6. When you first visited your baby, were you given enough information about the neonatal unit?

7. Do you feel prepared for your baby's discharge from this neonatal unit?

8. Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?

9. Were health professionals on the NNU sensitive to your emotions & feelings?

- Data analysis demonstrated that the parents were happy to complete all questions with good level of completeness reported.

- Neonatal staff and parent feedback templates have been developed and will be piloted over the next six-months to (Appendix Three & Four). These will be placed in relevant social areas for staff and parents to promote the RDQ and to provide timely, quarterly, summary feedback which is unbiased and easy to understand. This will include any changes which have been implemented in response to parental feedback.

3.1.3 Strengths

- The NNNI RDQ has been designed in accordance with the validated 2010/11 parents' experiences of neonatal care survey from the Picker Institute Europe[5], as recommended by the National Institute of Clinical Excellence.[6] This facilitates national benchmarking. In addition, the RDQ Task and Finish group provided further input thereby giving the tailored RDQ local ownership.

- The NNNI RDQ was piloted and revised based on feedback from neonatal unit staff, TinyLife and experts in the area.[4]

- The co-ordinated approach of quarterly, feedback to each NNU ensures that NNU ward managers can discuss findings at relevant Health & Social Care Trust Committees.

- The multidisciplinary PEG will be used as a means for timely dissemination to parents such as making the findings available on the TinyLife website.

3.1.4 Weaknesses

- RDQ coverage, although comparable to national figures, could be improved to a level similar to that attained during the pilot phase. Some parent groups were under-represented in the analyses particularly where the infant remained on the unit for a short time period.

- There were some delays in the initiation of data collection in some units which may have impacted negatively on coverage.

- Timing of completion of the RDQ may have inflated perceived performance due to a number of compounding factors such as insufficient time for parents to reflect on experiences at an already busy time just before discharge. As discussed previously these issues will be explored further by the PEG.

Table 9: Benchmarking NNNI with other UK networks (Picker Institute Europe, parents' experiences of neonatal care survey 2014).

RDQ Question	NNNI 2014/15 Yes, definitely	Picker 2014 Equivalent	Picker 2014 Q number
When you visited the unit, did staff caring for your baby introduce themselves to you?	97%	63%	C1
When you first visited the unit, did staff show you how to wash your hands using the 7-step technique?	91%	79%	C4
Did a member of neonatal staff talk to you about your baby's condition and treatment after the birth?	94%	-	-
When you first visited your baby, were you given enough information about the neonatal unit?	92%	62%	C2
Were you given information about help you could get with travelling expenses, parking costs or food vouchers?	61%	29%	F5
Was the equipment surrounding your baby explained fully to you?	87%	57%	C3
Did you feel you were able to talk to staff on the unit about your worries and concerns?	95%	79%	C6
Were health professionals on the neonatal unit sensitive to your emotions and feelings?	94%	Nurses 76% Doctors 70%	C8 C9
Did staff keep you up to date with your baby's condition and progress?	95%	81%	D4
In your opinion, was important information about your baby passed from one member of staff to another?	92%	73%	C10
When you asked questions about your baby's condition and treatment, did you get answers you could understand?	93%	79%	F1
If you (and/or your partner or companion) wanted to stay overnight to be close to your baby, did the hospital offer you comfortable accommodation?	86%	63%	E4
Were you able to contact the neonatal unit by telephone whenever you needed to?	98%	-	-
While you were there, did staff wash their hands or use hand gel before touching your baby?	99%	-	-
If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?	98%	78%	D8
If you wanted to breast feed your baby, were you given enough support from the neonatal unit staff to do this?	95%	75%	D11
Were you happy with breastfeeding facilities within your unit?	94%	-	-
If you wanted to bottle feed your baby were you given enough support from the neonatal unit staff to do this?	96%	76%	D12
Were you or your partner or companion involved in the day-to-day care of your baby?			
Nappy changing?	94%	-	-
Feeding?	93%	-	-
Skin-to-skin contact/kangaroo care?	87%	60%	D2
Overall, did staff help you feel confident in caring for your baby?	97%	81%	D7
Did you feel prepared for your baby's discharge from the neonatal unit?	94%	75%	G4
Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?	93%	-	-

3.2 Recommendations

- Positive responses to the RDQ by parents, health professionals and academics indicate that the RDQ data collection, analyses and reporting should be integrated into NNNI activities on a routine basis as part of the ongoing monitoring of neonatal outcomes.

- RDQ quarterly feedback provision to NNUs using the agreed templates (Appendix Three).

- Inclusion of a parent representative on the Parent Engagement Group.

- Provision of RDQ parental feedback using agreed templates (Appendix Four).

- Consideration should be given to an Annual NNNI shared learning workshop to promote good practice using RDQ findings.

- Consideration should be given to RDQ translation into the three most common international languages.

- Consideration should be given to the development of an RDQ supplemental post-discharge survey focusing on the transition home and family post-discharge support.

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Appendix One: Neonatal Network NI: Parental Engagement Group Terms of Reference

Aim: The Parental Engagement Group has evolved from the completion of the RDQ Task & Finish Group, recognising the need to ensure a continuous family focus as central to the network. The group will work to support the process of engagement and participation with neonatal families and strive to ensure issues that affect families are addressed through the neonatal work plan.

Membership (with Neonatal Network Board designation)

- David Millar: NNNI Network Information Lead, BHSCT (Chair)
- Fiona Alderdice: Director of Research, School of Nursing & Midwifery, QUB
- Sally Hamilton: Discharge coordinator BHSCT
- Angela Hughes: ANNP, WHSCT
- Alison McNulty: Lay Member, Tiny Life
- Emma McCall: NICORE Project Manager, QUB
- Amy McAuley: NICORE Health Research Assistant, PHA
- Claire McGinley: NNNI Project Manager, HSCB
- Steven Guy: SANDS
- Janet Lambrechts: Ward Manager NNU, NHSCT
- Sharon Ferguson: Ward Sister, SEHSCT
- Colm Darby: CAH NNU SHSCT & Neonatal Nurse Association Rep.
- Clifford Mayes: NNNI Clinical Lead Neonatal Network (BHSCT)

Frequency of Meetings: The group will meet quarterly to support parental engagement becoming embedded in the network approach.

Accountability: The group will report to the NNNI Board through the chair.

Main Focus:

1. Build on the engagement work to date commissioned by the network in collaboration with QUB and Tiny Life.

2. Support the implementation of the RDQ service improvement tool across units as a benchmarking tool and a feedback mechanism for staff and families.

3. Review network plans to ensure a partnership approach between staff and families is incorporated and where possible drives the agenda.

Appendix Two: Regional Discharge Questionnaire 2015/16

Unit Code:

NNNI
Neonatal Network Northern Ireland

Your Experience of Neonatal Care

We would like you to tell us about your experiences while your baby was in Neonatal care. These questions are anonymous and you or your baby will not be identified. Your baby's medical care will not change in any way if you say no. Your views are very important to us and will be shared with the staff to help us improve the care we provide for babies and their families in our neonatal unit. They may also be used as part of an annual report. Thank you for taking the time to complete this questionnaire.

About your baby:

1. When your baby was born how many completed weeks of pregnancy were you (gestational age of your baby)? (please circle one option)

   Less than 28 | 28 to 31 weeks | 32 to 33 weeks | 34 to36 weeks | 37 weeks or more

2. How long was your baby in our neonatal unit? (please circle one option)

   Less than 1 day | Between 1 & 7 days | Between 8 days & 8 weeks | More than 8 weeks

3. If your baby is being transferred out from this unit to another neonatal unit or hospital (e.g. Royal Belfast Hospital for Sick Children), did staff clearly explain to you why your baby is being transferred? (please tick)

   Yes definitely ☐ | Yes to some extent ☐ | No ☐ | Baby not being transferred ☐

4. If your baby is going home or to the postnatal ward, overall since birth how long has your baby been in hospital? (please circle one option) Not Applicable

   Less than 1 day | Between 1 & 7 days | Between 8 days & 8 weeks | More than 8 weeks

5. Which hospital or neonatal unit(s) has your baby previously been admitted to? (please circle all that apply)

   No previous admissions | Altnagelvin | Craigavon | Daisy Hill | Antrim | Ulster

   South West Acute (Erne) | Royal Maternity | Royal Belfast Hospital for Sick Children

About your baby's care:

Please tick the box which represents your opinion/feeling regarding the service you received:

	Always/ nearly always	Sometimes	Never	Unsure/ forgotten
6. When you visited the unit, did staff caring for your baby introduce themselves to you?	☐	☐	☐	☐
7. When you first visited the unit, did staff show you how to wash your hands using the 7 step technique?	☐	☐	☐	☐
8. Did a member of neonatal staff talk to you about your baby's condition and treatment after the birth?	☐	☐	☐	☐
9. In the first few days, were you given enough information about the neonatal unit?	☐	☐	☐	☐
10. Were you given information about help you could get with travelling expenses, parking costs or food vouchers?	☐	☐	☐	☐
11. Was the equipment surrounding your baby explained fully to you?	☐	☐	☐	☐
12. Did you feel you were able to talk to staff on the unit about your worries and concerns?	☐	☐	☐	☐
13. Were neonatal staff sensitive to your emotions and feelings?	☐	☐	☐	☐
14. Did staff keep you up to date with your baby's condition and progress?	☐	☐	☐	☐
15. Was there good communication between the neonatal staff caring for your baby?	☐	☐	☐	☐
16. When any member of neonatal staff spoke to you about your baby's care was it easy to understand?	☐	☐	☐	☐
17. Were you able to reach the neonatal unit by telephone whenever you needed to?	☐	☐	☐	☐
18. While you were there, did staff wash their hands or use hand gel before touching your baby?	☐	☐	☐	☐

	Not Applicable	Always/ nearly always	Sometimes	Never	Unsure/ forgotten
19. If you (and/or your partner or companion wanted to stay overnight) to be close to your baby, did the hospital offer you adequate accommodation?	☐	☐	☐	☐	☐
20. If you wanted to express breast milk for your baby, were you given the support you needed from Neonatal staff?	☐	☐	☐	☐	☐

	Not Applicable	Always/ nearly always	Sometimes	Never	Unsure/ forgotten
21. If you wanted to breast feed your baby, were you given enough support from the Neonatal staff to do this?	☐	☐	☐	☐	☐
22. Were the breastfeeding facilities within the unit adequate?	☐	☐	☐	☐	☐
23. If you bottle fed your baby were you given enough support from the neonatal staff to do this?	☐	☐	☐	☐	☐

24. Were you and your partner or companion involved in the day-to-day care of your baby?

	Always/ nearly always	Sometimes	Never	Unsure/ forgotten
Nappy changing	☐	☐	☐	☐
Feeding	☐	☐	☐	☐
Skin-to-Skin (kangaroo) care	☐	☐	☐	☐
Comfort and soothing	☐	☐	☐	☐
25. Overall, did staff help you feel confident in caring for your baby?	☐	☐	☐	☐

	Yes definitely	Yes to some extent	No	Unsure/ forgotten
26. Do you feel prepared for your baby's discharge from this neonatal unit?	☐	☐	☐	☐
27. Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?	☐	☐	☐	☐

	Temperature	Light level	Noise level	Cleanliness
28. Are there any of the following aspects of our neonatal unit which could be improved?	☐	☐	☐	☐

29. On a scale of one to ten where 1 is very poor and 10 is excellent, how would you rate your experience in our Neonatal unit?

Very poor 1 2 3 4 5 6 7 8 9 10 Excellent

Any other comments about your baby's care:

Please feel free to continue writing on the back of the sheet.

About you;

By answering the following questions you are helping us to consider the needs of families in our care when developing services.

30. Please tick the person(s) filling in this questionnaire?

Mother ☐ Father ☐ Other ☐ Please specify: .....

31. Please circle which age range (years) you fall within?

Less than 18 | 18 to 24 | 25 to 29 | 30 to 34 | 35 to 39 | 40 or over

32. Please tick which of the following best describes where you live?

Country ☐ Town/city ☐

33. Please circle you current marital status?

Single | Co-habiting | Married | Separated | Divorced | Other (please specify): .....

34. What is your and your partner's employment status? (please circle)

You:	Employed (full-time)	Employed (part-time)	Unemployed	Student
	Not Applicable			
Partner:	Employed (full-time)	Employed (part-time)	Unemployed	Student
	Not Applicable			

35. Do you consider yourself to belong to an ethnic or other minority group? (please tick)

No ☐ Yes ☐ if yes please specify .....

36. Approximately how long does it take you to travel to our Neonatal unit from your home? (please circle)

Less than 30 minutes | 30 minutes to 1 hour | 1 to 2 hours | More than 2 hours

37. Do you or your partner have a disability or special need? (Please tick for you and your partner)

You: No ☐ Yes ☐ Partner: Not Applicable ☐ No ☐ Yes ☐

38. Do you have any other children?

No ☐ Yes ☐ if yes, how many? .....

40. Please indicate when your baby was discharged from this neonatal unit? (*The information gathered will allow us to give feedback to each unit every three months and will be used for no other purpose.*)

1st April – 31 June (Q1) ☐ 1 July – 30 September (Q2) ☐

1 October – 31 December (Q3) ☐ 1 January - 31 March (Q4) ☐

Thank you for taking the time to complete this questionnaire.
Please place your questionnaire in the box provided.

Appendix Three: Neonatal Unit Summary Quarterly Feedback

NNNI Regional Discharge Questionnaire

Neonatal Network Northern Ireland

NNNI 2014/15

	Your Unit Coverage	NNNI (Network) Coverage
Number of Returned Questionnaires	(Number of live discharges) ()	**615 / 1974** (Number of live discharges) **(31.2%)**

About Your baby's care:	Your Unit							NNNI (Network)					
RDQ Question	Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR		Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR
6. When you visited the unit, did staff caring for your baby introduce themselves to you?								594/611 (97.2%)	17/611 (2.8%)	0/611 (0%)	0/611 (0%)	-	4
7. When you first visited the unit, did staff show you how to wash your hands using the 7 step technique?								560/613 (91.4%)	33/613 (5.4%)	16/613 (2.6%)	4/613 (0.7%)	-	2
8. Did a member of neonatal staff talk to you about your baby's condition and treatment after the birth?								572/610 (93.8%)	31/610 (5.1%)	3/610 (0.5%)	4/610 (0.7%)	-	5
9. When you first visited your baby, were you given enough information about the neonatal unit?								561/611 (91.8%)	42/611 (6.9%)	7/611 (1.1%)	1/611 (0.2%)	-	4
10. Were you given information about help you could get with travelling expenses, parking costs or food vouchers?								363/598 (60.7%)	98/598 (16.4%)	127/598 (21.2%)	10/598 (1.7%)	-	17
11. Was the equipment surrounding your baby explained fully to you?								533/611 (87.2%)	63/611 (10.3%)	12/611 (2.0%)	3/611 (0.5%)	-	4
12. Did you feel you were able to talk to staff on the unit about your worries and concerns?								578/611 (94.6%)	32/611 (5.2%)	1/611 (0.2%)	0/611 (0%)	-	4
13. Were health professionals on the NNU sensitive to your emotions & feelings?								572/610 (93.8%)	34/610 (5.6%)	2/610 (0.3%)	2/610 (0.3%)	-	5

About your babies care:	Your Unit							NNNI (Network)					
RDQ Question	Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR		Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR
14. Did staff keep you up to date with your baby's condition and progress?								580/611 (94.9%)	28/611 (4.6%)	1/611 (0.2%)	2/611 (0.3%)	-	4
15. In your opinion, was important information about your baby passed from one member of staff to another?								557/608 (91.6%)	39/608 (6.4%)	3/608 (0.5%)	9/608 (1.5%)	-	7
16. When you asked questions about your baby's condition and treatment, did you get answers you could understand?								566/610 (92.8%)	41/610 (6.7%)	3/610 (0.5%)	0/610 (0%)	-	5
17. If you (and/or your partner or companion) wanted to stay overnight did the hospital offer you comfortable accommodation?								478/554 (86.3%)	41/554 (7.4%)	25/554 (4.5%)	10/554 (1.8%)	33	28
18. Were you able to contact the NNU by telephone whenever you needed to?								592/605 (97.9%)	9/605 (1.5%)	2/605 (0.3%)	2/605 (0.3%)	-	10
19. While you were there, did staff wash their hands/ use hand gel before touching baby?								606/610 (99.3%)	4/610 (0.7%)	0/610 (0%)	0/610 (0%)	-	5

Feeding your baby:	Your Unit							NNNI (Network)					
RDQ Question	Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR		Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR
20. If you wanted to express breast milk, were you given the support you needed from NNU Staff?								421/431 (97.7%)	9/431 (2.1%)	0/431 (0%)	1/431 (0.2%)	163	21
21. If you wanted to breast feed your baby, were you given enough support from the NNU staff to do this?								344/364 (94.5%)	20/364 (5.5%)	0/364 (0%)	0/364 (0%)	236	15
22. Were you happy with the breast feeding facilities within your unit?								351/372 (94.4%)	18/372 (4.8%)	3/372 (0.8%)	0/372 (0%)	217	26
23. If you wanted to bottle feed your baby were you given enough support from the NNU staff to do this?								486/508 (95.7%)	20/508 (3.9%)	2/508 (0.4%)	0/508 (0%)	84	23

Day to day care of your baby:	Your Unit							NNNI (Network)					
RDQ Question	Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR		Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR
24. Were you and your partner or companion involved in the day to day care of your baby?													
Nappy changing								572/610 (93.8%)	34/610 (5.6%)	4/610 (0.7%)	-	-	5
Feeding								568/608 (93.4%)	33/608 (5.4%)	7/608 (1.2%)	-	-	7
Skin-to-Skin (Kangaroo) care?								497/570 (87.2%)	43/570 (7.5%)	30/570 (5.3%)	-	-	45
25. Overall, did staff help you feel confident in caring for your baby?								595/612 (97.2%)	17/612 (2.8%)	0/612 (0%)	0/612 (0%)	-	3

Preparing for Discharge:	Your Unit							NNNI (Network)					
RDQ Question	Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR		Yes, definitely	Yes, to some extent	No	Unsure/ Forgotten	NA	NR
26. Do you feel prepared for your baby's discharge from this neonatal unit?								568/605 (93.9%)	34/612 (5.6%)	3/605 (0.5%)	0/605 (0%)	-	10
27. Were you informed that you could contact the neonatal unit for advice and reassurance in the initial discharge period?								556/599 (92.8%)	25/599 (4.2%)	11/599 (1.8%)	7/599 (1.2%)	-	16

Overall Rating:

RDQ Question	Your Unit						NNNI (Network)				
	Light level	Temp	Noise level	Cleanliness	Baby's comfort		Light level	Temp	Noise level	Cleanliness	Baby's comfort
28. Are there any aspects of our neonatal unit which could be improved?							15/615 (2.4%)	40/615 (6.5%)	15/615 (2.4%)	2/615 (0.3%)	6/615 (1.0%)

Overall Parental Experience:

29. On a scale of one to ten where 1 is very poor and 10 is excellent, how would you rate your experience in our neonatal unit?			
		Your Unit Score	**NNNI Score**
Unit Max Score (UMS) 10*number of responses	Total Unit Actual Score (TUAS) Sum (all actual scores)	% Rating (UMS/TUAS*100)	**5964/6100**
920 (1 non responder)			**97.8% Rating**

Demographics:

Gestational age group (completed weeks)	**Your Unit Percentage (XX/XX*100)**	**Northern Ireland Percentage (XX/XX*100)**
less than 28		4.4%
28 to 30		11.0%
31 to 33		19.5%
34 to 36		28.7%
Term (37 or more)		36.3%
No response		6 Cases
Total RDQs		**615**
Length of stay in our unit (this admission)	**Your Unit Percentage (XX/XX*100)**	**Northern Ireland Percentage (XX/XX*100)**
less than 1 day		1.3%
Between 1 day and 1 week		35.1%
Between 1 week and 8 weeks		55.7%
More than 8 weeks		7.9%
No response		8 Cases
Total RDQs		**615**

Your Unit Feedback Comments:

In total, XX respondents provided comments of which XX(XX.X %) were positive in nature. XX respondents highlighted issues for improvement and XX had mixed views regarding their neonatal experience. Comments were categorised as follows:

		Comments
Valid	Facilities or comfort	
	general	
	communication	
	information	
	visiting	
	Standardisation	
	Feeding	
	Total	

Issues for consideration:

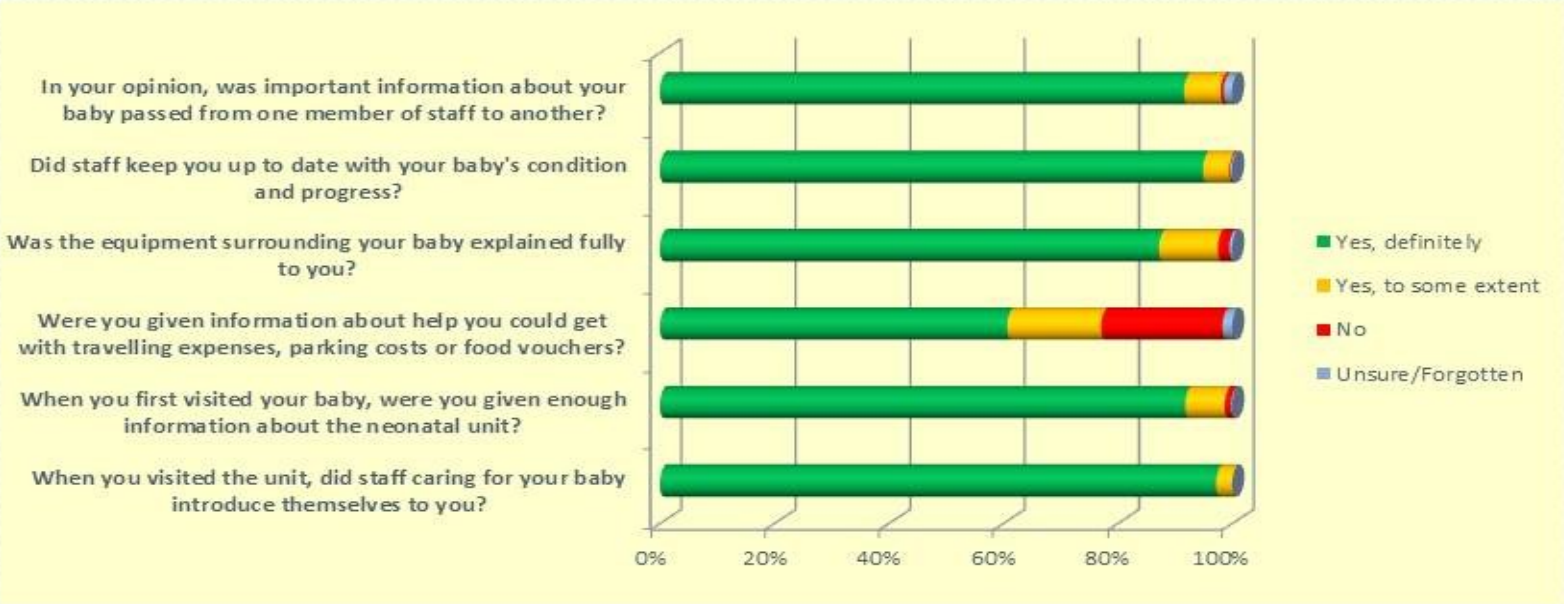
Positive Comments:

For Further information:

Contact: e.mccall@qub.ac.uk.

Appendix Four: Parent Summary Quarterly Feedback

NNNI Our Parent Experiences 2014/15 Information



Quote:

"Staff were all very helpful and friendly and kept us informed of baby's progress everyday. The operation and diagnosis was drawn and explained in a manner which we understood."

NNNI Our Parent Experiences 2014/15 Information

Experience – Yes, definitely	NNU1	NNU2	NNU3	NNU4	NNU5	NNU6	NNU7	NNNI
When you visited the unit, did staff caring for your baby introduce themselves to you?	94%	100%	100%	97%	96%	99%	96%	97%
When you first visited your baby, were you given enough information about the neonatal unit?	90%	93%	94%	91%	96%	93%	88%	92%
Were you given information about help you could get with travelling expenses, parking costs or food vouchers?	73%	69%	78%	43%	39%	78%	39%	61%
Was the equipment surrounding your baby explained fully to you?	87%	91%	92%	75%	96%	94%	83%	87%
Did staff keep you up to date with your baby's condition and progress?	91%	93%	100%	94%	96%	97%	96%	95%
In your opinion, was important information about your care passes from one member of staff to another?	87%	95%	94%	90%	94%	93%	90%	92%

Quote: "

Staff more than helpful. All very friendly. Our son was looked after very well and we were always well informed of his progress."

NNNI
Neonatal Network Northern Ireland

" All staff were fantastic. The care we received has been outstanding and we cannot speak highly enough of all staff." Craigavon NICU

" The staff here have been very professional and caring towards our baby and us as parents. They provided a helping hand for us during this difficult time..." Royal Maternity NICU

"....I can't say we had a single negative experience. World class." Altnagelvin NICU

"...the thought of my babies going into neonatal care was scary, but all staff have been amazing and any baby going into neonatal is in very good hands....." Antrim NICU

"....The neonatal team in the SWA were fantastic, always giving great care to the boys and reassuring myself and my husband." South West Acute SCBU

" ....the staff are amazing and they looked after our wee man in a caring and professional manner. 100% aesfect. " Daisy Hill SCBU

Important

Please Complete Our Parent Survey before Discharge or Transfer

" ....In a very fluid situation we were kept informed and up-to-date with all aspects of care." Ulster NICU