

# Parents' experiences of neonatal care: Findings from Neonatal Survey 2014

Executive Summary

March 2015

Sarah-Ann Burger

[www.pickereurope.org](http://www.pickereurope.org)

## Picker Institute Europe

Picker Institute Europe is an international charity dedicated to ensuring the highest quality health and social care for all, always. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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## Introduction

Assessing parents' experiences of neonatal services is crucial for an understanding of how the quality of care can be improved. By ensuring that organisations carry out the survey in a consistent and systematic way, it is possible to build up a national picture of parents' experiences of neonatal care and, with caution, to compare the performance of different organisations, monitor change over time, and identify variations between different groups of respondents. Such findings can be used at a local level to drive improvements in overall experiences of neonatal services.

This document summarises the findings from the Neonatal Survey 2014 carried out by the Picker Institute in collaboration with Bliss (the charity "for babies born too soon, too small, too sick") and NHS England who kindly part-funded the survey. The purpose of the survey was to understand the experience of parents whose baby received care in a neonatal unit, to assist units in understanding where they are doing well and what could be improved.

The survey involved 88 hospital neonatal units from 72 NHS trusts in England (including special care baby units, local neonatal units and neonatal intensive care units), in addition to the neonatal services at Jersey General Hospital. Participating units fell into 13 different neonatal networks across England.

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

- Wave 1: sample of babies discharged from neonatal care between October 2013 and March 2014
- Wave 2: sample of babies discharged from neonatal care between April and September 2014

For each neonatal unit, a sample of up to 100 parents per wave whose babies were consecutively discharged alive<sup>1</sup> were sent a questionnaire to complete at home. Questionnaires were mailed to parents between May and December 2014 and up to two reminders were sent to non-responders.

Parents aged 16 and over were eligible for the survey if their baby had received neonatal care for 24 hours or longer and had been discharged home during the specified sampling periods.

A total of 15,944 eligible parents were sent a questionnaire. Responses were received from 6000 parents, a response rate of 37.6%.

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<sup>1</sup> If a unit had fewer than 100 babies discharged in the sampling period then all eligible parents were included in the survey.

## Key Findings

This section provides an overview of the key findings, focusing on those areas where parents reported their most positive and least positive experiences of neonatal care. Those questions showing the greatest variation across neonatal networks in parents' experiences are also highlighted.

### Positive Parent Experience

The results presented here are based on the scores calculated for each question in the survey. For an explanation of how scores are calculated and should be interpreted, refer to Section 1 of the main report.

Table 1. Question areas where parents reported the most positive experience

| Question  | Score |
|---|-------|
| <b>G3</b> Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit?               | 95    |
| <b>E5</b> Were you able to visit your baby on the unit as much as you wanted to?  | 95    |
| <b>C13</b> Overall, did you have confidence and trust in the staff caring for your baby?  | 92    |
| <b>G6</b> How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment? | 91    |
| <b>B4</b> After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?                  | 91    |
| <b>C5</b> Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?                    | 90    |
| <b>C12</b> Did staff refer to your baby by his/her first name?  | 90    |
| <b>D4</b> Were you told about any changes in your baby's condition or care?   | 89    |
| <b>D7</b> Overall, did staff help you feel confident in caring for your baby?   | 89    |
| <b>D1</b> Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?          | 89    |

### Key areas for improvement

Table 2. Question areas where parents reported the least positive experience

| Question   | Score |
|--|-------|
| <b>F4</b> Were you offered emotional support or counselling services from neonatal unit staff?   | 57    |
| <b>B3</b> After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?  | 55    |
| <b>A2</b> Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth?                                      | 54    |
| <b>F2</b> Were you given enough written information to help you understand your baby's condition and treatment?  | 53    |
| <b>F6</b> Did staff give you any information about parent support groups, such as Bliss or other local groups?   | 53    |
| <b>F5</b> Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/parking expenses, hardship fund or food vouchers)? | 41    |

## Variations across networks

Some differences in parental experiences by neonatal network were revealed. Overall, Greater Manchester and Trent Perinatal networks had the highest proportion of parents responding positively to most questions compared to other networks, whereas the London network had the greatest room for improvement.

Questions with the largest variation of positive feedback from parents across networks include:

- B2: After you gave birth, were you offered a photograph of your baby?
- D5: When a ward round was taking place, were you allowed to be present when your baby was being discussed?
- G3: Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit?
- A2: Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth?
- D6: Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?
- E4: If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?
- F5: Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/parking expenses, hardship fund or food vouchers)?
- B3: After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?
- C12: Did staff refer to your baby by his/her first name?

For a detailed breakdown of results by network, please refer to Section 4 of the main report.

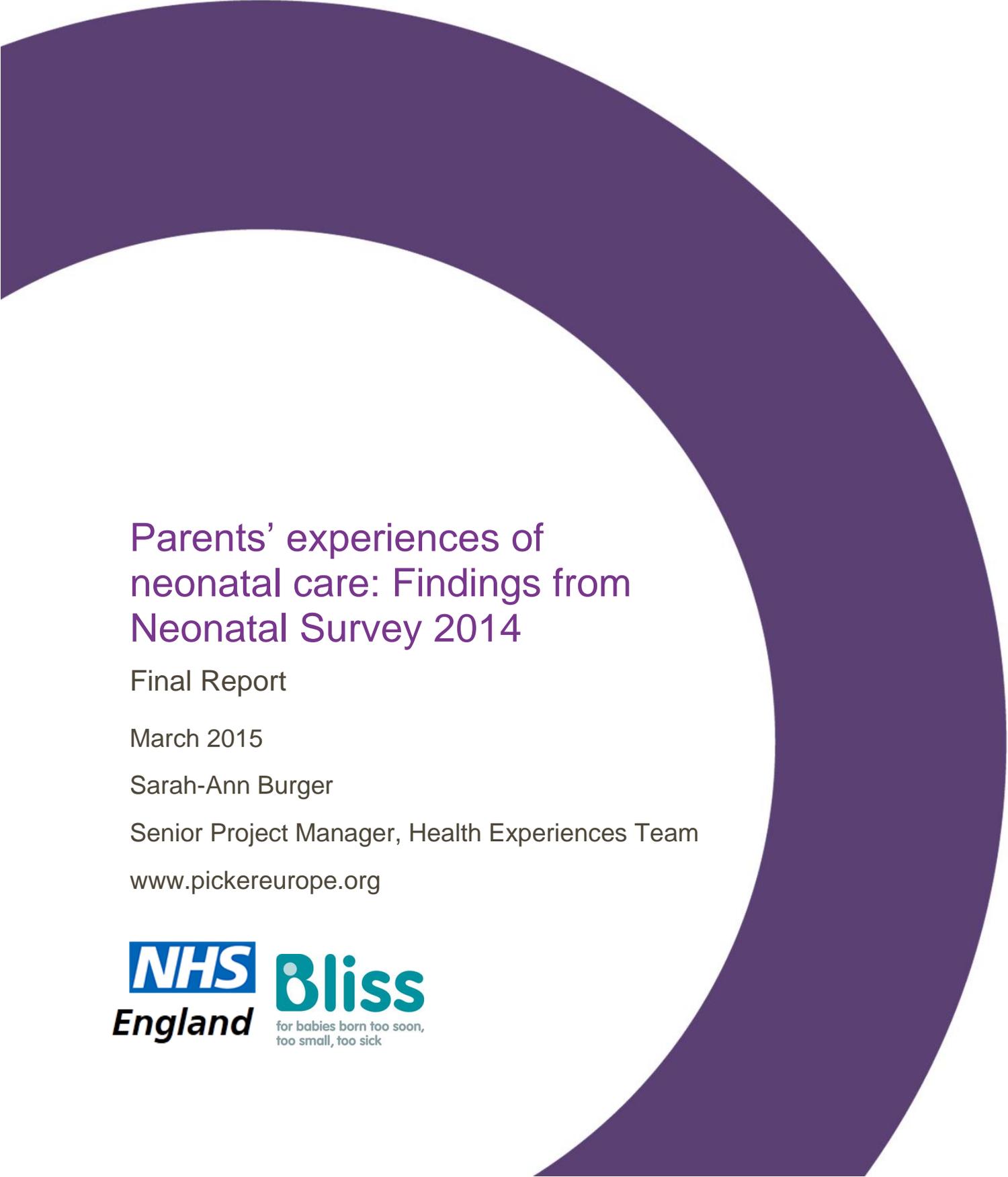
## Individual unit reports

Each neonatal unit that participated in the 2014 Neonatal Survey will receive an individual report of their findings to use locally to drive improvement. These reports include:

- Overall score for each question
- Benchmarking against units of the same type (i.e. LNU, SCBU, NICU)
- Benchmarking against the overall average score
- Benchmarking against units of the same network
- Overall frequency tables
- Freetext comments from parents

## Conclusion and Next Steps

The neonatal survey 2014 results indicate areas of good performance in addition to highlighting where there is room for improvement. Communicating results and priorities for service improvement across organisations and in local areas, will be key to ensuring that changes are implemented successfully. Patients and staff should be involved in developing action plans and any resulting quality improvement activities. Therefore, the Picker Institute are hosting two regional workshops to assist units with interpreting their results and identifying areas for improvement.



# Parents' experiences of neonatal care: Findings from Neonatal Survey 2014

Final Report

March 2015

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Section One

## Introduction



## Background

Assessing parents' experiences of neonatal services is crucial for an understanding of how the quality of care can be improved. By ensuring that organisations carry out the survey in a consistent and systematic way, it is possible to build up a national picture of parents' experiences of neonatal care and, with caution, to compare the performance of different organisations, monitor change over time, and identify variations between different groups of respondents. Such findings can be used at a local level to drive improvements in overall experiences of neonatal services.

The results presented in this report are the overall results of all participating neonatal units in England from the Neonatal Survey 2014, carried out by the Picker Institute in collaboration with Bliss (the charity "for babies born too soon, too small, too sick") and NHS England who kindly part-funded the survey. The purpose of the survey was to understand the experience of parents whose baby received care in a neonatal unit, to assist units in understanding where they are doing well and what could be improved.

## The Questionnaire

In 2010, Bliss (the charity "for babies born too soon, too small, too sick") approached researchers at the Picker Institute to develop a questionnaire, in conjunction with the neonatal networks, to examine parents' experiences of neonatal care. The survey was implemented in 2010-2011 with 125 English neonatal units, including special care baby units (SCBUs), local neonatal units (LNUs), and neonatal intensive care units (NICUs).

The survey was repeated in 2014 in order to:

- give NHS Trusts and neonatal units in England another opportunity to assess parental experiences of neonatal care and benchmark against other participating organisations using a standardised methodology;
- monitor performance and measure the impact of any quality improvement initiatives introduced since the last survey.

For the 2014 survey the Picker Institute, in collaboration with Bliss and NHS England, refined and updated the questionnaire following a consultation exercise with neonatal network leads. Some relatively minor survey changes were made to ensure that the questions were consistent with current service provision. The amended survey was cognitively tested using three rounds of cognitive interviews with 12 parents whose baby had recently received care in a neonatal unit. Cognitive testing involves interviews to go through the questionnaire with members of the target group to ensure that the survey questions are appropriate and relevant, and interpreted as intended, to maximise the validity of the data that they collect.

The updated 2014 survey of parents' experiences of neonatal care was offered to all NHS Trusts and units in England. The survey was promoted via communications from the Picker Institute, Bliss and NHS England. 72 NHS trusts (88 hospital neonatal units) in England signed up to the survey (including special care baby units, local neonatal units and neonatal intensive care units), in addition to the neonatal services at Jersey General Hospital.

## Survey methodology

Picker Institute Europe coordinated the survey fieldwork, which was conducted in two waves in order to obtain a sufficiently sized sample to allow the results to be presented at unit-level:

- Wave 1: sample of babies discharged from neonatal care between October 2013 and March 2014
- Wave 2: sample of babies discharged from neonatal care between April and September 2014

For each unit, a sample of up to 100 parents whose babies were consecutively discharged alive from the neonatal unit were sent a questionnaire to complete at home<sup>1</sup>. Questionnaires were mailed to parents' between May and December 2014 and up to two reminders were sent to non-responders. Parents aged 16 and over were eligible for the survey if their baby had received neonatal care for 24 hours or longer and had been discharged home during the specified sampling periods.

Parents were sent a questionnaire, a covering letter from the trust, a multiple language sheet offering help with the survey, and a FREEPOST envelope. Parents wishing to complete the survey filled it in and returned it to the Picker Institute in the FREEPOST envelope. Non-responders were sent a reminder letter after 2-3 weeks, and another questionnaire and final reminder letter after a further 2-3 weeks.

The Picker Institute ran a Freephone helpline for patients who had any queries or concerns about the survey. This included links to LanguageLine with immediate access to interpreters in over 100 languages. Parents wishing to opt-out of the survey could do so by returning the questionnaire blank, or by calling the Freephone helpline. A total of 73 calls were received, which included 1 LanguageLine request.

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<sup>1</sup> If a unit had fewer than 100 babies discharged in the sampling period then all eligible parents were included in the survey.

## Interpreting this report

The results present the overall findings for all participating units, in addition to:

- breakdowns by network and,
- breakdowns by unit type (NICU, SCBU, LNU).

The percentage calculations throughout the report **exclude respondents that did not answer**. Full frequency tables are included at the end of the report in Appendix A, which display the number of missing responses for each question, along with details of who and how many people answered, and the proportion of patients that selected each response option. Please note that differences between networks, and unit type have not been tested for statistical significance.

The data have been 'standardised' by the age of respondents and by the gestational age of the baby at birth. The only exception to this approach is in section H on the demographics as it is more appropriate to present the real percentage figures rather than standardised data for these questions.

### Scores

For findings presented in Section 3 'Overall Results' the individual responses to questions in the survey were converted into scores on a scale of 0 to 100. A score of 100 represents the best possible response. Therefore, the higher the score for each question, the better the units are performing. The overall score for each question is calculated as an average of the individual scores. The scores are not percentages, so a score of 80 does not mean that 80% of parents who experienced neonatal care have had a particular experience (e.g. ticked 'Yes' to a particular question), it means that the overall scores is 80 out of a maximum of 100. A 'scored' questionnaire showing the scores assigned to each question is available upon request.

Not all response options are able to be scored; many questions within the questionnaire include an option that cannot be used to evaluate the unit's performance. For example, if a respondent cannot remember or does not know the answer to a question, a score is not given. It is also not appropriate to score all questions within the questionnaire for benchmarking purposes. This is because not all questions assess the neonatal units in any way, or they may be 'filter questions' designed to filter out respondents to whom following questions do not apply. An example of a filter question would be A1 "Before your baby was born, did you know that they might need care in a neonatal unit?"

### Graphs

In Section 4 and Section 5 of the report, findings are presented as graphs. These are arranged by questionnaire section. The graphs included in this report display percentages for each question, comparing networks and the national average (section 3), and by unit type and the national average (section 4). For questions that measure performance, the graphs use a range of **red**, **amber** and **green** to present the percentage of people who responded positively (green), less positively, (amber) or negatively (red) to a specific question.

## Confidence intervals

As the survey was not of all parents who responded rather than all parents, the results may not be exactly the same as if everyone had responded. However, we can estimate the level of confidence we should have in the results by considering the confidence interval surrounding the results. The table below shows the level of confidence we would have for various numbers of respondents.

| <u>Number of respondents</u> | <u>Confidence Interval (+/-)</u> |
|------------------------------|----------------------------------|
| 50                           | 12.0%                            |
| 100                          | 8.5%                             |
| 200                          | 6.0%                             |

Example: For a particular question, 200 patients responded, of which 25% answered 'yes'.

From the table above, we can see that for 200 respondents the confidence interval would be +/- 6.0%. We would therefore estimate that the true results could be between 19.0% and 31.0%. However, if only 50 patients responded, and 25% answered 'yes', the confidence intervals would be +/- 12% so the true result could be between 13% and 37%.

## Rounding of percentages

Note that throughout the report, partial percentages have been rounded to the nearest full number. For example 12.8% is rounded up to 13%, while 5.3% would be rounded down to 5%.

## Overall average

The overall average is based on results from the 87 hospital neonatal units in England who participated in the survey. The overall average excludes Jersey General Hospital as they are a non-NHS provider.

## Individual unit reports

Each neonatal unit that participated in the Neonatal Survey 2014 receives an individual report of their findings to use locally to drive improvement. The report aims to assist units to identify key areas for improvement from the perspective of parents. Results are presented in a few ways including:

- Overall score for each question
- Benchmarking against units of the same type (i.e. LNU, SCBU, or NICU)
- Benchmarking against the overall average score
- Benchmarking against units of the same network
- Overall frequency tables
- Freetext comments from parents

Section Two

## Survey Response

*Response rates and demographics*



## Response Rates

This section displays the response rate for each NHS neonatal unit that participated in the survey, as well as the overall response rate for each network.

Overall, responses were received from 6000 parents, a response rate of **37.6%**. Trent Perinatal Network received the highest response rate (46%, n=242), whereas South West Midlands Maternity and Newborn Network (31%, n=346) had the lowest response rate compared to other networks.

Table 1. Response rates by neonatal units and respective networks.

| Network  | Unit                                   | Eligible Invited | Returned   | Response Rate |
|--|--|------------------|------------|---------------|
| <b>Cheshire and Merseyside Neonatal Network</b>      | Arrowe Park Hospital                   | 193              | 57         | 30%           |
|  | Whiston Hospital                       | 148              | 42         | 28%           |
|  | Alder Hey Hospital                     | 86               | 41         | 48%           |
|  | Liverpool Women's Hospital             | 296              | 90         | 30%           |
|  | Macclesfield District General Hospital | 99               | 42         | 42%           |
|  | Countess Of Chester Hospital           | 196              | 82         | 42%           |
|  | Ormskirk & District General Hospital   | 130              | 54         | 42%           |
|  | Warrington Hospital                    | 200              | 82         | 41%           |
|  | <b>Total</b>                           | <b>1348</b>      | <b>490</b> | <b>36%</b>    |
| <b>Greater Manchester Neonatal Network</b>           | Wythenshawe Hospital                   | 189              | 26         | 14%           |
|  | Royal Bolton Hospital                  | 193              | 68         | 35%           |
|  | Royal Albert Edward Infirmary          | 124              | 48         | 39%           |
|  | St Mary's Hospital, Manchester         | 197              | 72         | 37%           |
|  | North Manchester General Hospital      | 194              | 76         | 39%           |
|  | Royal Oldham Hospital                  | 198              | 82         | 41%           |
|  | <b>Total</b>                           | <b>1095</b>      | <b>372</b> | <b>34%</b>    |
| <b>Lancashire and South Cumbria Neonatal Network</b> | Royal Preston Hospital                 | 198              | 68         | 34%           |
|  | <b>Total</b>                           | <b>198</b>       | <b>68</b>  | <b>34%</b>    |

Table 1. *continued*

| Network                                  | Unit  | Eligible Invited | Returned    | Response Rate |
|--|---|------------------|-------------|---------------|
| <b>London Neonatal Network</b>           | The Royal London Hospital                     | 193              | 20          | 10%           |
|  | Whipps Cross University Hospital              | 194              | 18          | 9%            |
|  | Newham General Hospital                       | 194              | 17          | 9%            |
|  | The Royal Free Hospital                       | 144              | 51          | 35%           |
|  | Kingston Hospital                             | 196              | 89          | 45%           |
|  | Ealing Hospital                               | 125              | 30          | 24%           |
|  | King George Hospital                          | 178              | 53          | 30%           |
|  | Queen's Hospital, Romford                     | 181              | 53          | 29%           |
|  | St Thomas' Hospital                           | 199              | 87          | 44%           |
|  | University Hospital Lewisham                  | 199              | 96          | 48%           |
|  | Queen Elizabeth Hospital Woolwich             | 142              | 47          | 33%           |
|  | St George's Hospital                          | 192              | 88          | 46%           |
|  | Chelsea & Westminster Hospital                | 195              | 91          | 47%           |
|  | University College Hospital                   | 199              | 76          | 38%           |
|  | Northwick Park Hospital                       | 183              | 40          | 22%           |
|  | St Mary's Hospital                            | 175              | 53          | 30%           |
| Queen Charlotte's And Chelsea Hospital   | 178   | 63               | 35%         |               |
|  | <b>Total</b>                                  | <b>3067</b>      | <b>972</b>  | <b>32%</b>    |
| <b>Midlands Central Newborn Network</b>  | Queen's Hospital, Burton Upon Trent           | 91               | 49          | 54%           |
|  | University Hospital Coventry                  | 196              | 78          | 40%           |
|  | George Eliot Hospital                         | 181              | 61          | 34%           |
|  | Northampton General Hospital                  | 182              | 72          | 40%           |
|  | Leicester Neonatal Service                    | 196              | 83          | 42%           |
|  |   | <b>Total</b>     | <b>846</b>  | <b>343</b>    |
| <b>South East Coast Neonatal Network</b> | Frimley Park Hospital                         | 199              | 106         | 53%           |
|  | Medway Maritime Hospital                      | 197              | 75          | 38%           |
|  | St Peter's Hospital                           | 185              | 82          | 44%           |
|  | East Surrey Hospital                          | 197              | 96          | 49%           |
|  | William Harvey Hospital                       | 211              | 81          | 38%           |
|  | The Queen Elizabeth The Queen Mother Hospital | 180              | 64          | 36%           |
|  | Conquest Hospital                             | 181              | 66          | 36%           |
|  |   | <b>Total</b>     | <b>1350</b> | <b>570</b>    |

Table 1. *continued*

| Network  | Unit                                       | Eligible Invited | Returned   | Response Rate |
|--|--|------------------|------------|---------------|
| <b>South West Midlands Maternity and Newborn Network</b>                               | Birmingham Women's Hospital                | 634              | 196        | 31%           |
|  | Birmingham Heartlands Hospital             | 95               | 29         | 31%           |
|  | Good Hope Hospital                         | 99               | 34         | 34%           |
|  | Alexandra Hospital                         | 74               | 28         | 38%           |
|  | Worcestershire Royal Hospital              | 211              | 59         | 28%           |
|  | <b>Total</b>                               | <b>1113</b>      | <b>346</b> | <b>31%</b>    |
| <b>South West Neonatal Network</b>   | Yeovil District Hospital                   | 120              | 54         | 45%           |
|  | St Michael's Hospital                      | 191              | 80         | 42%           |
|  | Musgrove Park Hospital                     | 198              | 94         | 47%           |
|  | Royal Cornwall Hospital                    | 182              | 86         | 47%           |
|  | Royal Devon And Exeter Hospital            | 197              | 93         | 47%           |
|  | Derriford Hospital                         | 198              | 77         | 39%           |
|  | The Great Western Hospital                 | 198              | 103        | 52%           |
|  | Gloucestershire Royal Hospital             | 187              | 62         | 33%           |
|  | Southmead Hospital                         | 196              | 93         | 47%           |
|  | <b>Total</b>                               | <b>1667</b>      | <b>742</b> | <b>45%</b>    |
| <b>Thames Valley and Wessex Neonatal Network</b>                                       | St Mary's Hospital, Isle Of Wight          | 145              | 46         | 32%           |
|  | Wexham Park Hospital                       | 196              | 70         | 36%           |
|  | Milton Keynes Hospital                     | 195              | 79         | 41%           |
|  | Princess Anne Hospital                     | 193              | 87         | 45%           |
|  | Queen Alexandra Hospital                   | 193              | 82         | 42%           |
|  | Salisbury District Hospital                | 135              | 79         | 59%           |
|  | Horton General Hospital                    | 65               | 28         | 43%           |
|  | John Radcliffe Hospital                    | 187              | 92         | 49%           |
|  | Stoke Mandeville Hospital                  | 197              | 79         | 40%           |
|  | <b>Total</b>                               | <b>1506</b>      | <b>642</b> | <b>43%</b>    |
| <b>The Staffordshire, Shropshire &amp; Black Country Newborn and Maternity Network</b> | University Hospital Of North Staffordshire | 195              | 58         | 30%           |
|  | Russells Hall Hospital                     | 198              | 81         | 41%           |
|  | Princess Royal Hospital                    | 192              | 83         | 43%           |
|  | <b>Total</b>                               | <b>585</b>       | <b>222</b> | <b>38%</b>    |

Table 1. *continued*

| Network  | Unit   | Eligible Invited | Returned   | Response Rate |
|--|--|------------------|------------|---------------|
| <b>Trent Perinatal Network</b>                       | Nottingham City Hospital                             | 167              | 82         | 49%           |
|  | King's Mill Hospital                                 | 186              | 89         | 48%           |
|  | Queens Medical Centre                                | 169              | 71         | 42%           |
|  | <b>Total</b>   | <b>522</b>       | <b>242</b> | <b>46%</b>    |
| <b>Yorkshire &amp; Humber North Neonatal Network</b> | Bradford Royal Infirmary Maternity Unit              | 166              | 52         | 31%           |
|  | York Hospital  | 164              | 72         | 44%           |
|  | Scarborough Hospital                                 | 133              | 41         | 31%           |
|  | Leeds Neonatal Service                               | 392              | 176        | 45%           |
|  | Calderdale Royal Hospital                            | 197              | 74         | 38%           |
|  | Pinderfields General Hospital                        | 173              | 75         | 43%           |
|  | Dewsbury And District Hospital                       | 133              | 45         | 34%           |
|  | <b>Total</b>   | <b>1358</b>      | <b>535</b> | <b>39%</b>    |
| <b>Yorkshire &amp; Humber South Neonatal Network</b> | Sheffield Children's Hospital Neonatal Surgical Unit | 188              | 66         | 35%           |
|  | Rotherham District General Hospital                  | 146              | 54         | 37%           |
|  | Chesterfield Royal Hospital                          | 136              | 64         | 47%           |
|  | The Jessop Wing, Sheffield                           | 187              | 77         | 41%           |
|  | Diana Princess Of Wales Hospital                     | 194              | 44         | 23%           |
|  | Scunthorpe General Hospital                          | 195              | 55         | 28%           |
|  | Bassetlaw District General Hospital                  | 61               | 24         | 39%           |
|  | Doncaster Royal Infirmary                            | 182              | 72         | 40%           |
|  | <b>Total</b>   | <b>1289</b>      | <b>456</b> | <b>35%</b>    |

## About the respondents

A total of 15,944 eligible parents were sent a questionnaire. 6,000 returned completed questionnaires giving an overall response rate of 37.6%. 85% of respondents were the baby's mother, 2% were the baby's father, and 12% of parents completed the questionnaire together. Seven guardians completed the questionnaire (<1% of all respondents).

Table 2: Respondent characteristics

| <b>Respondent Characteristics</b>    | <b>n</b> | <b>%</b> |
|--------------------------------------|----------|----------|
| <i>Percentage of babies born at:</i> |          |          |
| Up to 29 weeks pregnant              | 490      | 8%       |
| 30 - 37 weeks pregnant               | 3107     | 52%      |
| 38 weeks pregnant or more            | 2362     | 40%      |
| <i>Age group (mother):</i>           |          |          |
| 16 - 18 years                        | 12       | <1%      |
| 19 - 24 years                        | 591      | 10%      |
| 25 - 29 years                        | 1366     | 23%      |
| 30 -34 years                         | 2030     | 34%      |
| 35 years and older                   | 1996     | 33%      |
| <i>Ethnic group (mother):</i>        |          |          |
| White                                | 4832     | 81%      |
| Mixed                                | 123      | 2%       |
| Asian or Asian British               | 632      | 11%      |
| Black or Black British               | 257      | 4%       |
| Chinese or Other ethnic group        | 154      | 3%       |
| <i>Network Type</i>                  |          |          |
| Local neonatal unit                  | 675      | 11%      |
| Neonatal intensive care unit         | 2841     | 47%      |
| Special care baby unit               | 2484     | 41%      |

Section Three

## Overall Results

*Overview of overall scores*



## Overall results

This section provides a broad overview of the main survey findings for all participating units by questionnaire section, as well as those areas where overall, parents reported their most positive and least positive experiences of neonatal care. The results presented here are the scores for each question in the survey for which this is suitable. For an explanation of how scores are calculated and should be interpreted, refer to Section 1.

The survey results, including breakdowns by neonatal network are discussed in more detail in Section 4.

Table 3. Overall score by questionnaire section

### A. Before your baby was born

*Higher scores are better*

| Question  | Score |
|---|-------|
| <b>A2</b> Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth? | 54    |

### B. Your baby's admission to neonatal care

| Question   | Score |
|--|-------|
| <b>B2</b> After you gave birth, were you offered a photograph of your baby?  | 63    |
| <b>B3</b> After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?  | 55    |
| <b>B4</b> After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted? | 91    |

### C. Staff on the neonatal unit

*Higher scores are better*

| Question  | Score |
|---|-------|
| C1 When you visited the unit, did the staff caring for your baby introduce themselves to you?                       | 79    |
| C2 Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents) | 76    |
| C3 Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?         | 73    |
| C4 Were infection control practices explained to you, such as hand washing and procedures for visitors?             | 85    |
| C5 Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?           | 90    |
| C6 Were you able to talk to staff on the unit about your worries and concerns?                                      | 88    |
| C7 Were you able to speak to a doctor about your baby as much as you wanted?  | 66    |
| C8 Were the nurses on the unit sensitive to your emotions and feelings?   | 85    |
| C9 Were the doctors on the unit sensitive to your emotions and feelings?  | 83    |
| C10 In your opinion, was important information about your baby passed on from one member of staff to another?       | 84    |
| C11 Did staff give you conflicting information about your baby's condition or care?                                 | 67    |
| C12 Did staff refer to your baby by his/her first name?   | 90    |
| C13 Overall, did you have confidence and trust in the staff caring for your baby?                                   | 92    |

## D. Your involvement in your baby's care

Higher scores are better

| Question  | Score |
|---|-------|
| D1 Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?                                       | 89    |
| D2 Did you have as much skin- to-skin contact with your baby as you wanted?   | 72    |
| D3 Did the neonatal staff include you in discussions about your baby's care and treatment?  | 78    |
| D4 Were you told about any changes in your baby's condition or care?  | 89    |
| D5 When a ward round was taking place, were you allowed to be present when your baby was being discussed?   | 80    |
| D6 Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?                               | 74    |
| D7 Overall, did staff help you feel confident in caring for your baby?  | 89    |
| D8 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?   | 86    |
| D9 When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as a breast pump and sterilisation equipment? | 87    |
| D10 Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby?  | 88    |
| D11 If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff?  | 84    |
| D12 If you fed your baby formula milk, were you given enough support to do this from neonatal staff?  | 85    |

## E. Environment and facilities

| Question   | Score |
|--|-------|
| E1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?   | 84    |
| E2 Was there enough space for you to sit alongside your baby's cot in the unit?  | 82    |
| E3 In your opinion, was there adequate security on the neonatal unit?  | 88    |
| E4 If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?   | 70    |
| E5 Were you able to visit your baby on the unit as much as you wanted to? (please only think about unit-related reasons and not personal reasons such as needing to care for other children) | 95    |

## F. Information and support for parents

*Higher scores are better*

| Question   | Score |
|--|-------|
| <b>F1</b> If you asked questions about your baby's condition and treatment, did you get answers you could understand?  | 88    |
| <b>F2</b> Were you given enough written information to help you understand your baby's condition and treatment?  | 53    |
| <b>F4</b> Were you offered emotional support or counselling services from neonatal unit staff?   | 57    |
| <b>F5</b> Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/parking expenses, hardship fund or food vouchers)? | 41    |
| <b>F6</b> Did staff give you any information about parent support groups, such as Bliss or other local groups?   | 53    |

## G. Leaving the neonatal unit

| Question  | Score |
|---|-------|
| <b>G3</b> Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit?               | 95    |
| <b>G4</b> Did you feel prepared for your baby's discharge from neonatal care?   | 86    |
| <b>G5</b> Were you given enough information on what to expect in terms of your baby's progress and recovery?                        | 76    |
| <b>G6</b> How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment? | 91    |

## Ranked Scores

This section presents the areas where overall, parents reported their most positive and least positive experience of neonatal care. Scores are ranked from highest to lowest. Those questions with the highest scores shows where overall participating neonatal units are doing well. Those with lower scores present where overall, units have the most room for improvement. For an explanation of how scores are calculated and should be interpreted, refer to Section 1. Higher scores are better.

Table 4. Ranked overall scores

### Score 90 +

| Question  | Score |
|---|-------|
| <b>G3</b> Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit?               | 95    |
| <b>E5</b> Were you able to visit your baby on the unit as much as you wanted to?  | 95    |
| <b>C13</b> Overall, did you have confidence and trust in the staff caring for your baby?  | 92    |
| <b>G6</b> How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment? | 91    |
| <b>B4</b> After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?                  | 91    |
| <b>C5</b> Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?                    | 90    |
| <b>C12</b> Did staff refer to your baby by his/her first name?  | 90    |

## Score 85 - 89

| Question  | Score |
|---|-------|
| D4 Were you told about any changes in your baby's condition or care?  | 89    |
| D7 Overall, did staff help you feel confident in caring for your baby?  | 89    |
| D1 Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?                                       | 89    |
| E3 In your opinion, was there adequate security on the neonatal unit?   | 88    |
| F1 If you asked questions about your baby's condition and treatment, did you get answers you could understand?  | 88    |
| C6 Were you able to talk to staff on the unit about your worries and concerns?  | 88    |
| D10 Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby?  | 88    |
| D9 When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as a breast pump and sterilisation equipment? | 87    |
| D8 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?   | 86    |
| G4 Did you feel prepared for your baby's discharge from neonatal care?  | 86    |
| C8 Were the nurses on the unit sensitive to your emotions and feelings?   | 85    |
| D12 If you fed your baby formula milk, were you given enough support to do this from neonatal staff?  | 85    |
| C4 Were infection control practices explained to you, such as hand washing and procedures for visitors?   | 85    |

## Score 79 - 84

| Question  | Score |
|---|-------|
| D11 If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff?      | 84    |
| C10 In your opinion, was important information about your baby passed on from one member of staff to another? | 84    |
| E1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?            | 84    |
| C9 Were the doctors on the unit sensitive to your emotions and feelings?                                      | 83    |
| E2 Was there enough space for you to sit alongside your baby's cot in the unit?                               | 82    |
| D5 When a ward round was taking place, were you allowed to be present when your baby was being discussed?     | 80    |
| C1 When you visited the unit, did the staff caring for your baby introduce themselves to you?                 | 79    |

## Score 70 - 79

| Question  | Score |
|---|-------|
| D3 Did the neonatal staff include you in discussions about your baby's care and treatment?                                  | 78    |
| C2 Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)         | 76    |
| G5 Were you given enough information on what to expect in terms of your baby's progress and recovery?                       | 76    |
| D6 Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times? | 74    |
| C3 Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?                 | 73    |
| D2 Did you have as much skin- to-skin contact with your baby as you wanted?   | 72    |
| E4 If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?                      | 70    |

## Score below 70

| Question  | Score |
|---|-------|
| C11 Did staff give you conflicting information about your baby's condition or care?   | 67    |
| C7 Were you able to speak to a doctor about your baby as much as you wanted?  | 66    |
| B2 After you gave birth, were you offered a photograph of your baby?  | 63    |
| F4 Were you offered emotional support or counselling services from neonatal unit staff?   | 57    |
| B3 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?  | 55    |
| A2 Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth?                                      | 54    |
| F2 Were you given enough written information to help you understand your baby's condition and treatment?  | 53    |
| F6 Did staff give you any information about parent support groups, such as Bliss or other local groups?   | 53    |
| F5 Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/parking expenses, hardship fund or food vouchers)? | 41    |

Section Four

## Overall Results by Network

*Overview by section*



## Overall Results by Network

This section shows the survey results for all participating neonatal units by network, and a comparison against the average results for all participating networks. Findings for Lancashire and South Cumbria Neonatal Network are not presented to maintain anonymity as there was only one participating unit from this network. Their results are however included in the overall average. The results are presented according to the sections in the questionnaire. Please refer to the frequency tables in Appendix A for the number of respondents to each question. Cross tabulations for each question by network is available upon request from the Picker Institute.

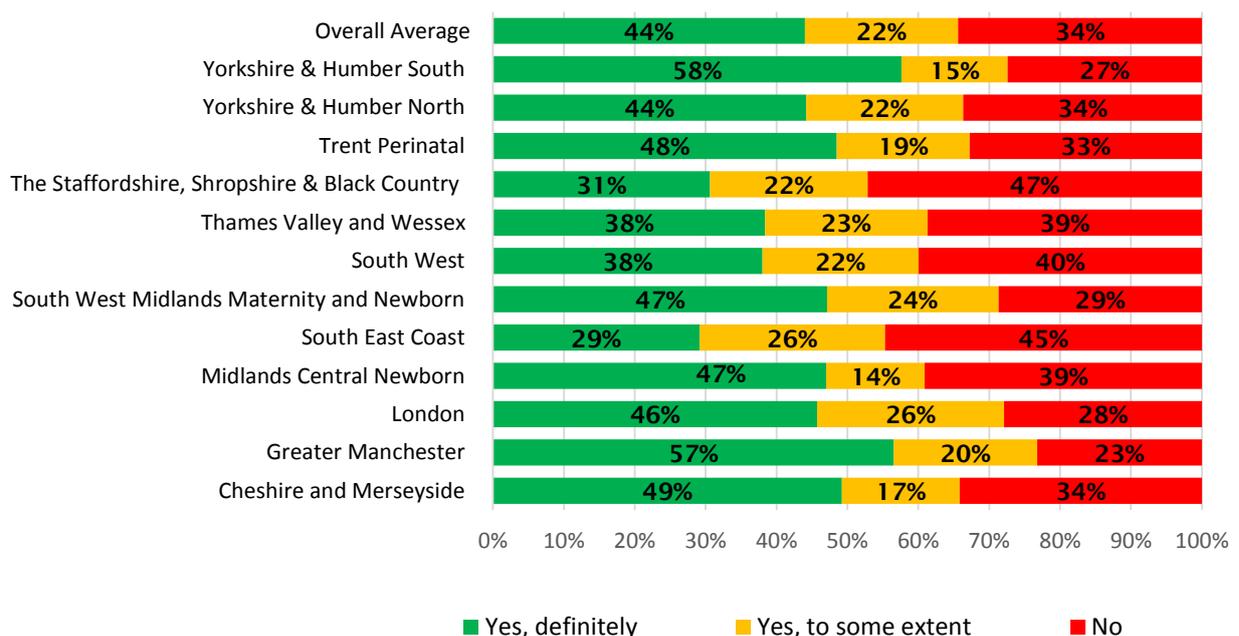
### A. Before your baby was born

Two thirds (66%; n=3880) of parents stated they did not know before their baby was born (i.e. during pregnancy or labour) that their baby might need care in a neonatal unit, compared to 34% (n=2031) who did.

Of those who did know, 44% (n=845) stated that staff from the neonatal unit definitely spoke to them about what to expect after the birth. 22% (n=405) noted this happened to some extent and 34% (n=669) said staff did not speak to them about what to expect. Parents from the Staffordshire, Shropshire and Black Country network (47%; n=31) were most likely to note that staff did not speak to them about what to expect compared to other networks. Those respondents from Yorkshire and Humber South network (58%, n=86) and Greater Manchester network (57%, n=80) were most likely to state that staff definitely spoke to them about what to expect after the birth compared to other networks. Refer to figure 1, graph A2 for full details.

### Figure 1: Section A. Graphs

**Graph A2. Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth? (Overall n=1919)**



## B. Your baby’s admission to neonatal care

Parents were asked about their experience of their baby’s admission to the neonatal unit. The parents responding from Yorkshire and Humber North network who were not discharged after they gave birth were least likely to share a ward with mothers who had their baby with them which bothered them (19%; n=83), compared to other networks (figure 2, graph B3). Younger mothers who were not discharged after they gave birth were more likely than older mothers to report that it bothered them when they were cared for in the same ward as mothers who had their baby with them (see table 5).

Table 5. Percentage of respondents to question B3, by age group

**B3. After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them? By mother’s age group (n=5198)**

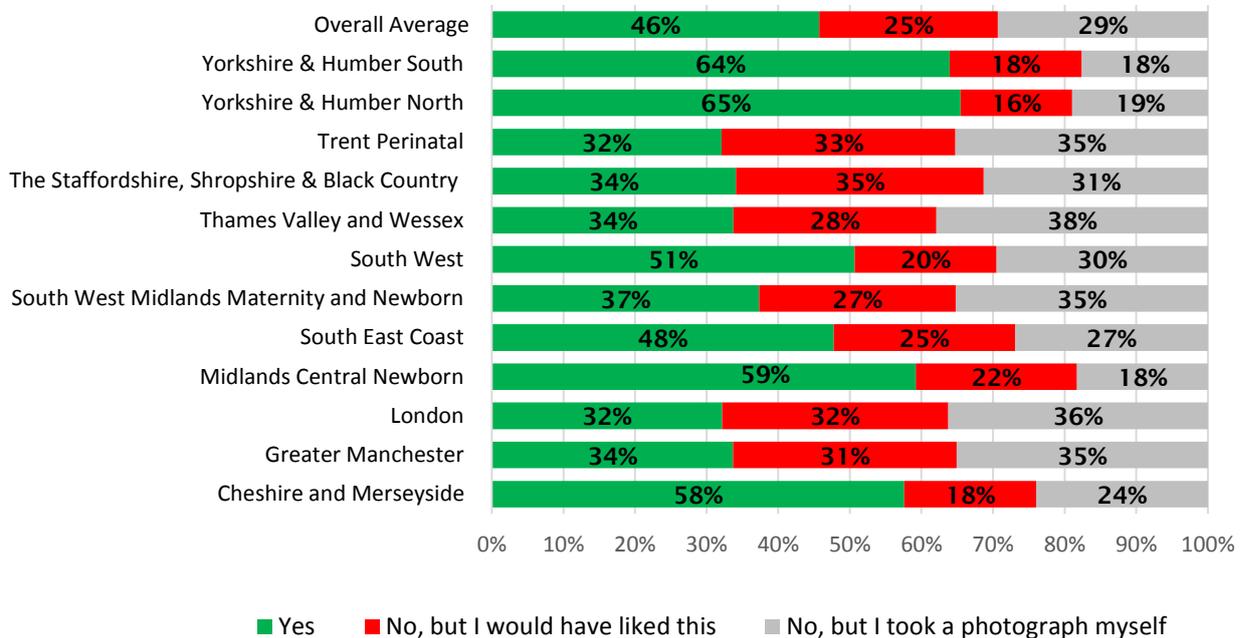
|   | 16-25 years | 26-29 years | 30-34 years | 35 + years |
|---|-------------|-------------|-------------|------------|
| <b>Yes, and this bothered me</b>            | 36.7%       | 32.6%       | 30.8%       | 27.3%      |
| <b>Yes, but I did not mind</b>              | 26.9%       | 25.7%       | 24.6%       | 31.5%      |
| <b>No, I stayed in a separate room/area</b> | 36.3%       | 41.7%       | 44.4%       | 41.2%      |

Compared with other units, a greater proportion of parents at Yorkshire and Humber North (65%; n=293) were offered photograph of their baby. Respondents from Trent Perinatal (32%; n=62) and London (32%; n=246) networks were least likely to be offered a photograph of their baby compared to other networks (figure 2, graph B2). 40% (n=197) of parents from South East Coast network stated that it bothered them that they shared a room with mothers who had their baby with them.

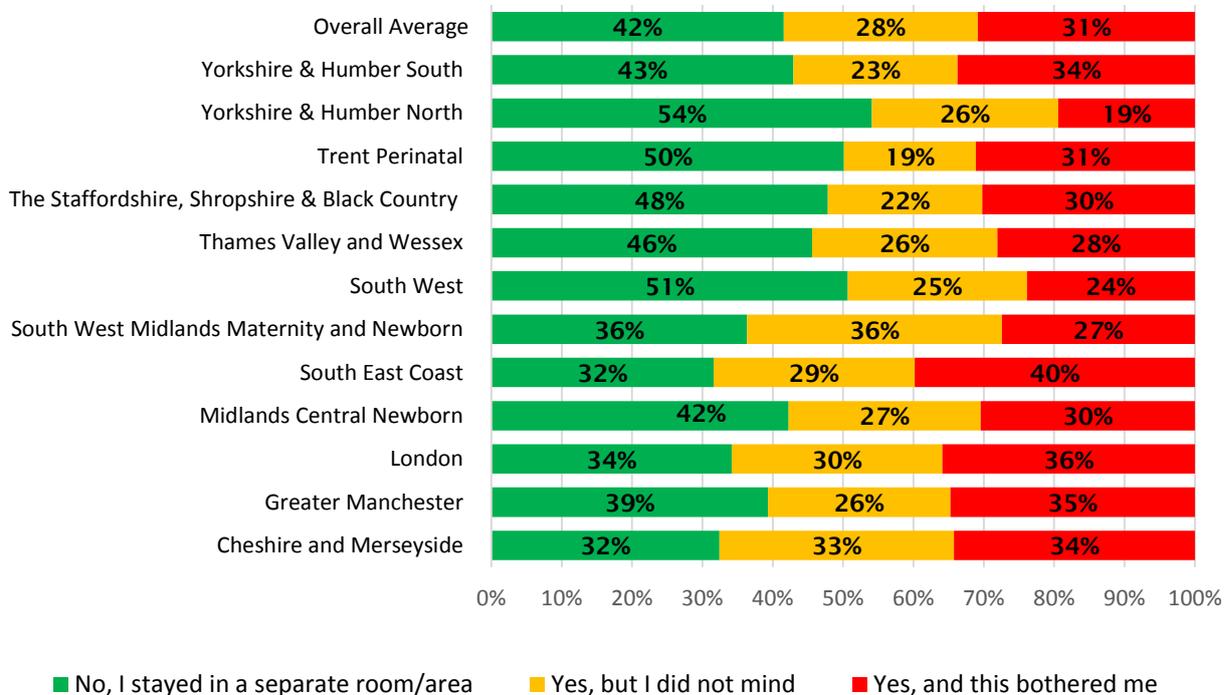
The results were similar across networks for parents being able to see their baby as soon as they wanted (see figure 2, graph B4).

## Figure 2: Section B. Graphs

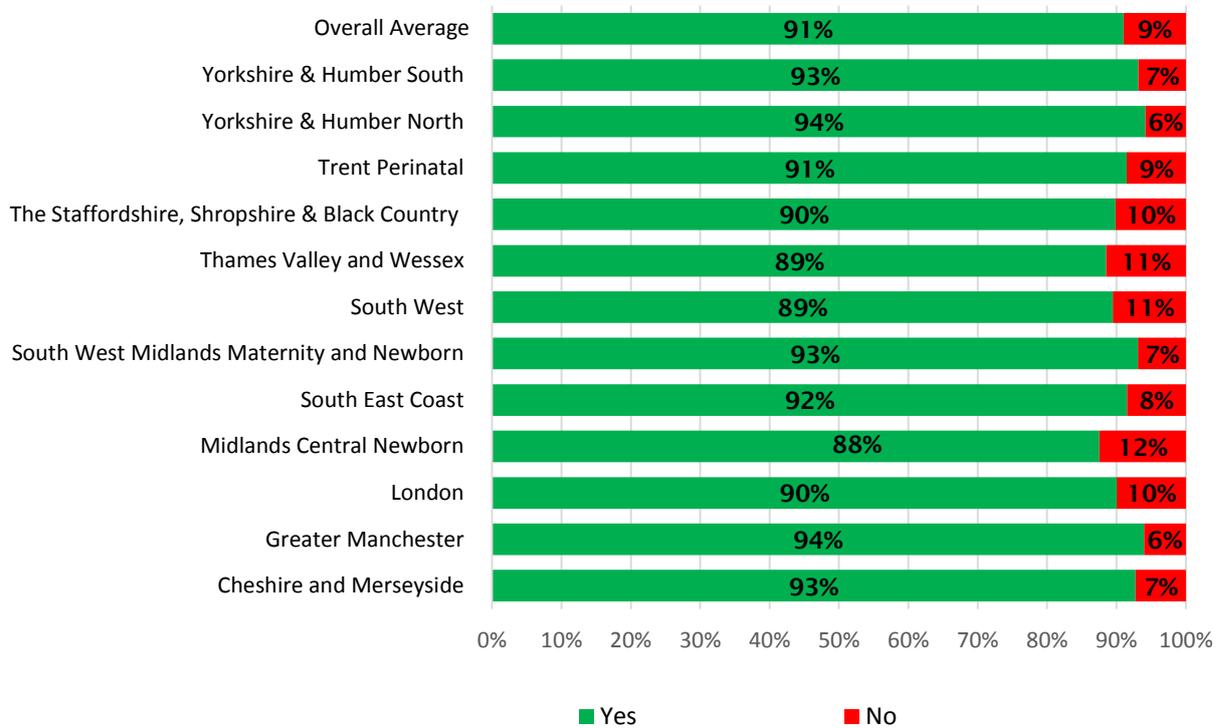
Graph B2. After you gave birth, were you offered a photograph of your baby? (Overall n=4972)



Graph: B3. After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them? (Overall n=5167)



**Graph B4. After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted? (Overall n=3858)**



### C. Staff on the neonatal unit

Figure 3 below maps the proportion of parents who responded positively to each question in section C “Staff on the neonatal unit” for all networks, and the overall average. It highlights the variations between networks for each question, and indicates that overall the London network has the most room for improvement. Whereas Trent Perinatal and Greater Manchester networks have the highest proportion of parents responding positively on most questions. The diagram also highlights the areas that most networks could improve such as: C7, parents being able to speak to doctors as much as they want to; C3, receiving information about the machines in the unit; and C11, parents receiving conflicting information from staff members. Higher percentages are better.

Overall, parents had confidence and trust in the staff caring for their baby, with 87% (n=5140) stating they always (or nearly always) had confidence and trust, 11% (n=667) sometimes did, and only 2% (n=112) stating they did not (figure 4, graph C13).

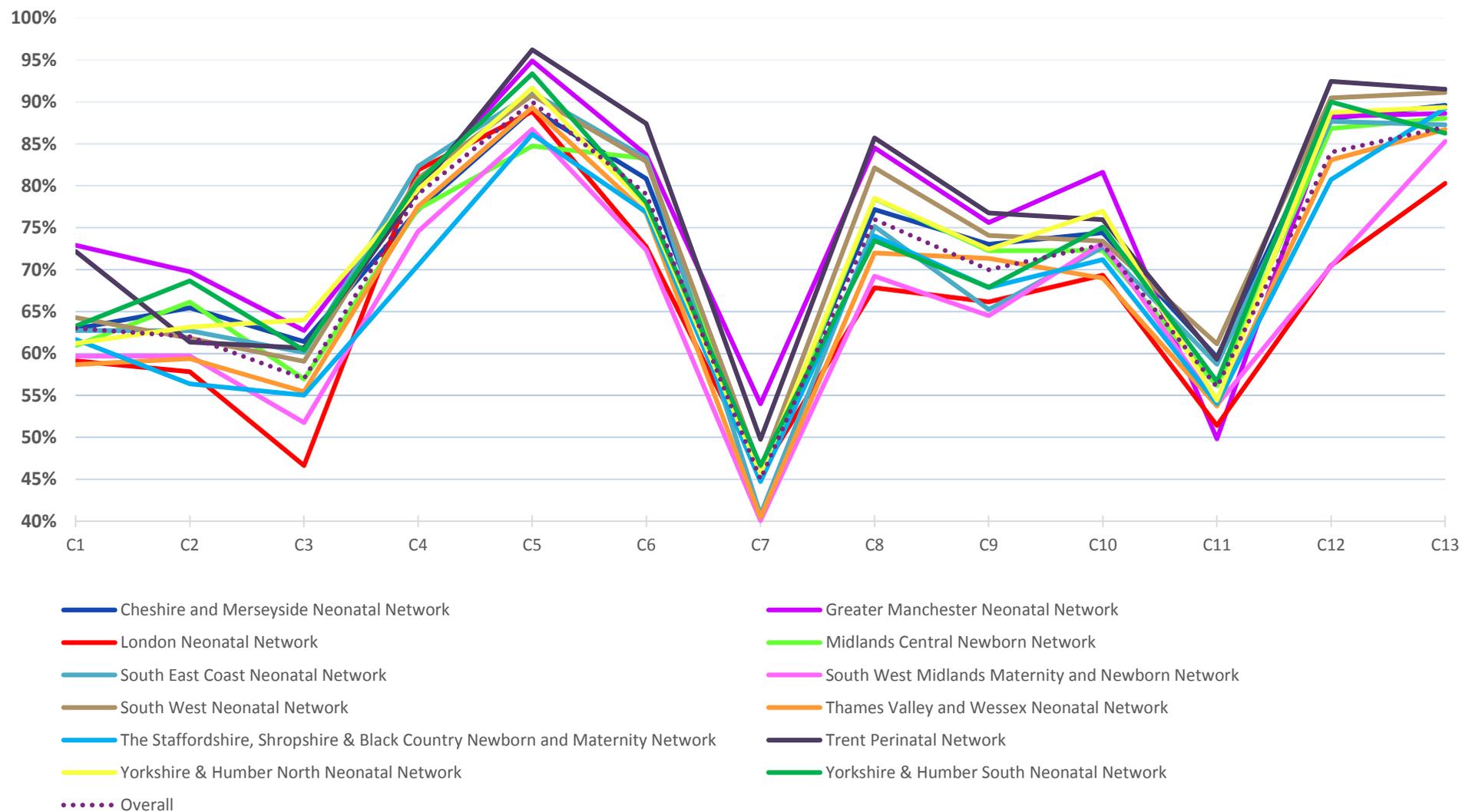
A high proportion of parents knew each day which nurse was responsible for their baby’s care. And for most networks parents stated that, where possible, staff referred to their baby by their first name. Trent Perinatal network had the highest proportion of parents (96%, n=230) stating they were always told which nurse was responsible for their baby’s care each day compared to other networks (figure 4, graph C5).

That said, overall a third of parents (33%; n=1911) noted that only some of the staff introduced themselves. Further, a large proportion (55%; n=3144) stated they were not fully able to talk to a doctor as much as they wanted. This trend was similar across all networks, however Greater Manchester network and Trent Perinatal network had the highest proportion of parents stating all staff introduced themselves and they could speak to doctors as much as they wanted (see figure 4, graphs C1 and C7 below).

Overall, parents were somewhat positive about doctors and nurses being sensitive to their emotions and feelings, and being able to talk to staff if they had worries or concerns (see figure 4, graphs C6, C8 and C9). However, approximately one third of respondents from the London network (32%; n=298) and South West Midlands network (31%; n= 99) stated that nurses were not fully sensitive to their emotions and feelings. Parents from the London, South East Coast, and South West Midlands networks were the mostly likely compared to other networks to report that doctors were not fully sensitive to their emotions and feelings (see figure 4, graph C9).

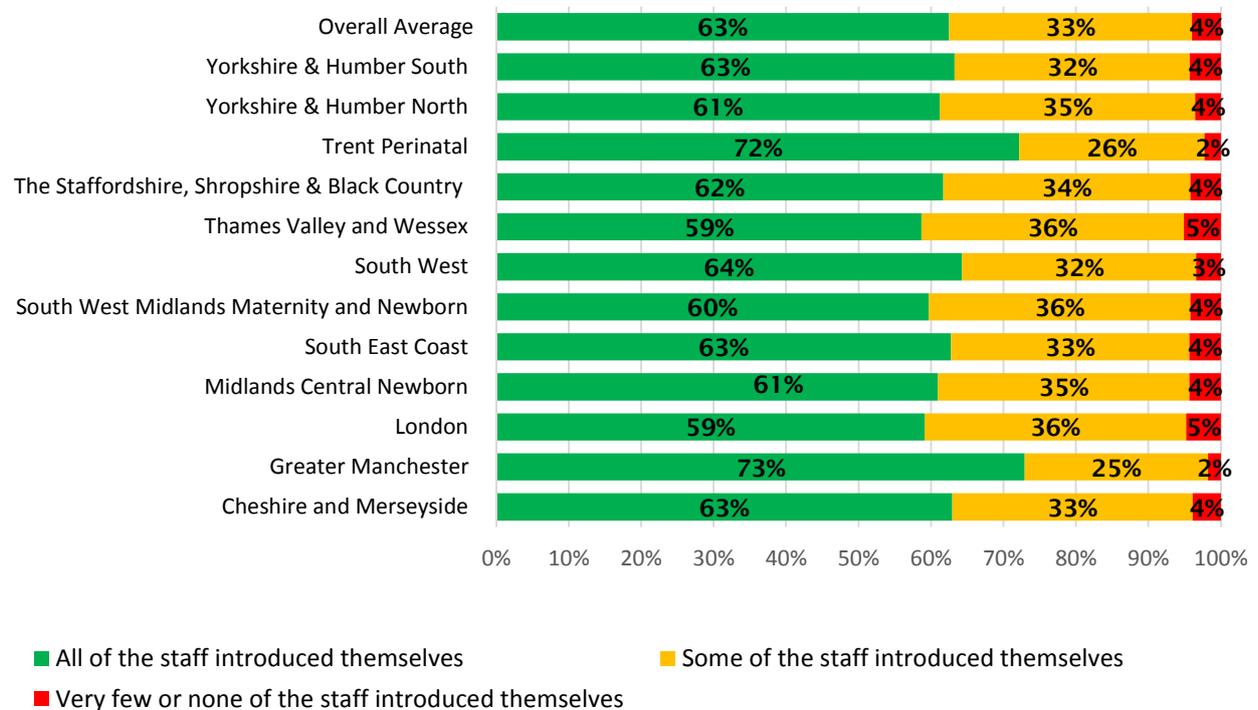
Sharing information about the neonatal unit as well as the purpose of machines, monitors and alarms could be improved across the networks with just less than half of parents stating this did not fully happen (see figure 4, graph C3). Parents mostly felt (73%, n=4078) that important information was passed on from one member of staff to another. However, only just over half of parents (56%; n=3300) stated they did not receive conflicting information about their baby’s condition or care, compared to 20% (n=1177) who stated they often received conflicting information, and 24% (n=1391) who sometimes did. Greater Manchester network had the highest proportion of parents stating that they did receive conflicting information compared to other networks (figure 4, graph C11).

**Figure 3- Neonatal Staff:**  
Proportion of parents who responded positively to all questions in section C, by network

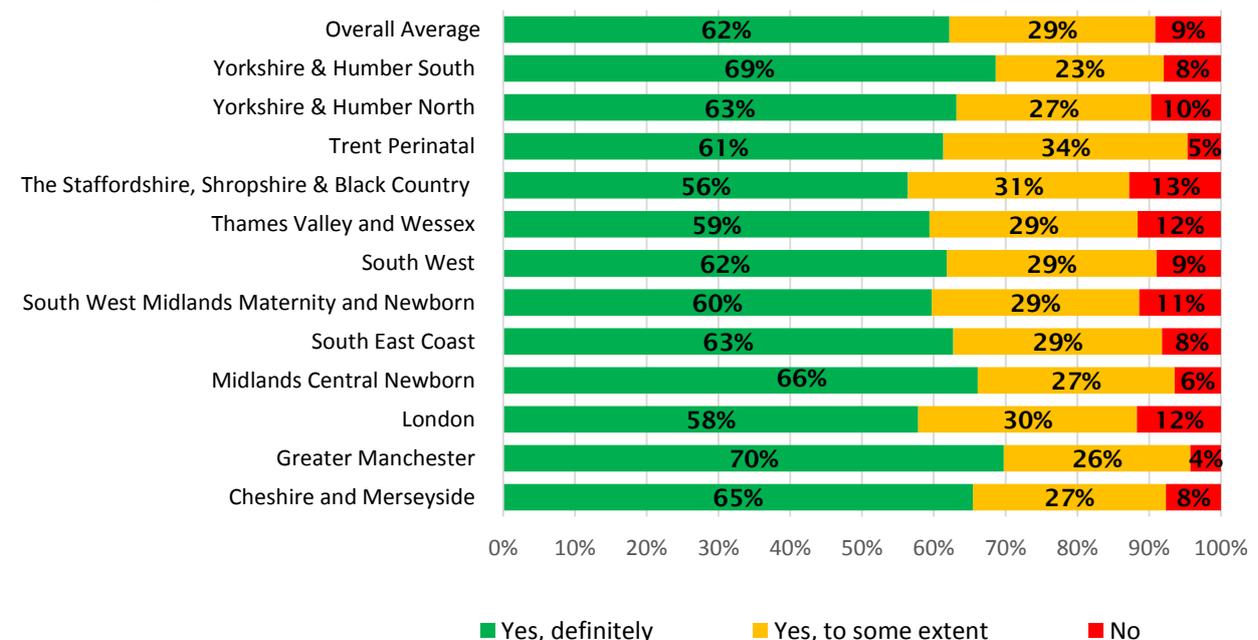


### Figure 4: Section C. Graphs

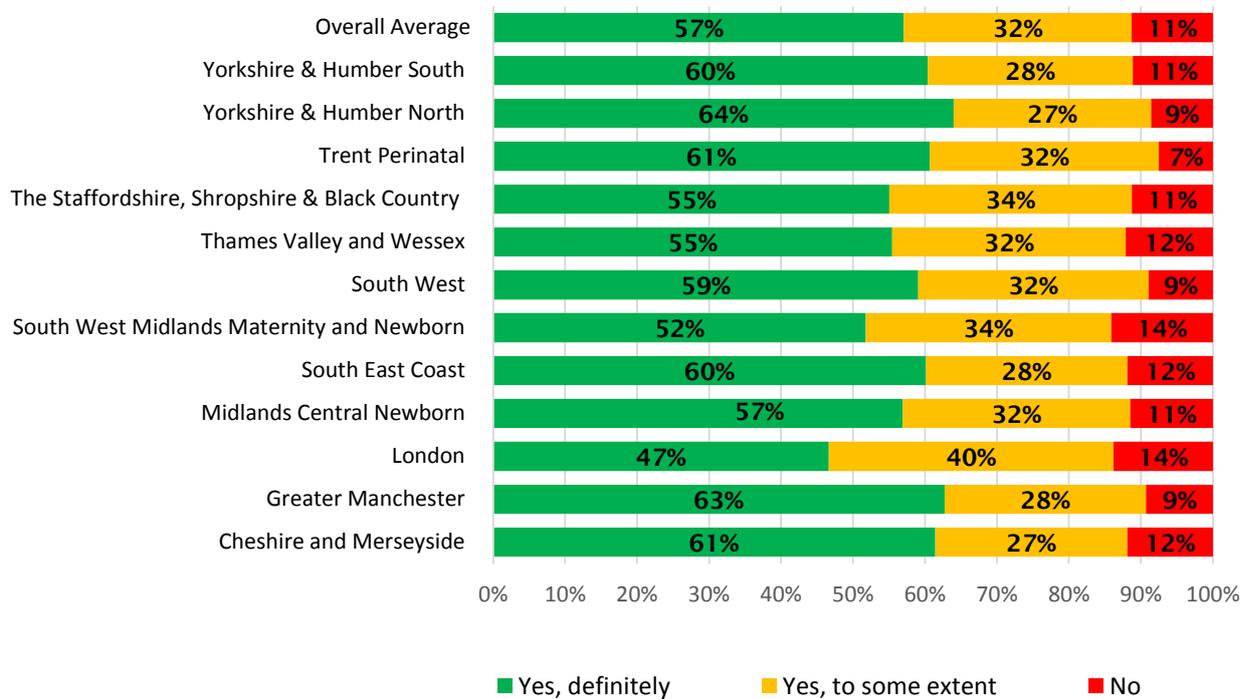
**Graph C1. When you visited the unit, did the staff caring for your baby introduce themselves to you?**  
(Overall n=5804)



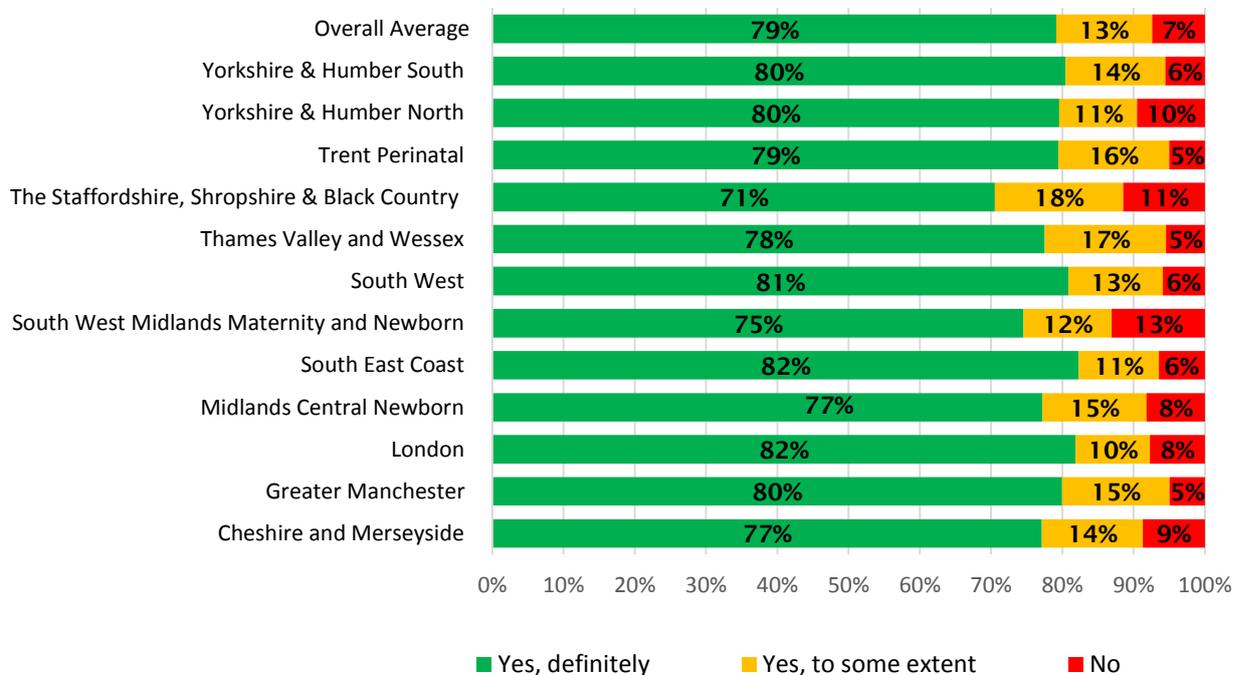
**Graph C2. Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents?)** (Overall n=5804)



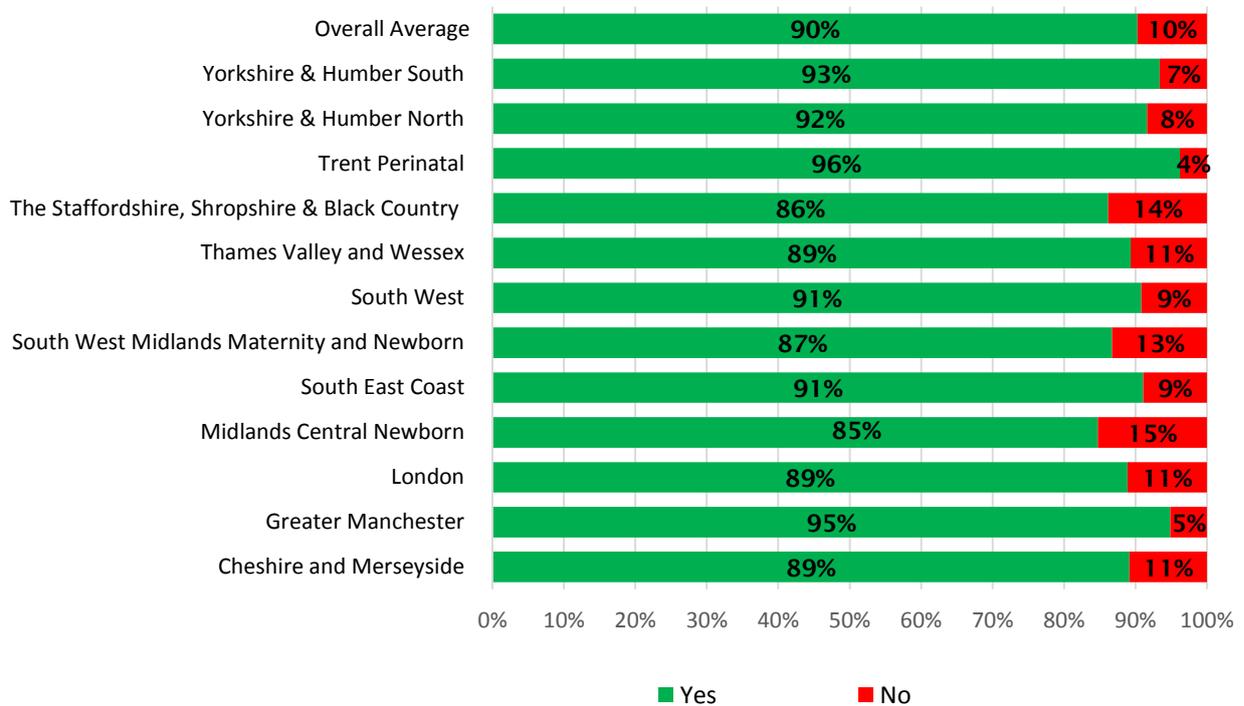
**Graph C3. Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you? (Overall n=5767)**



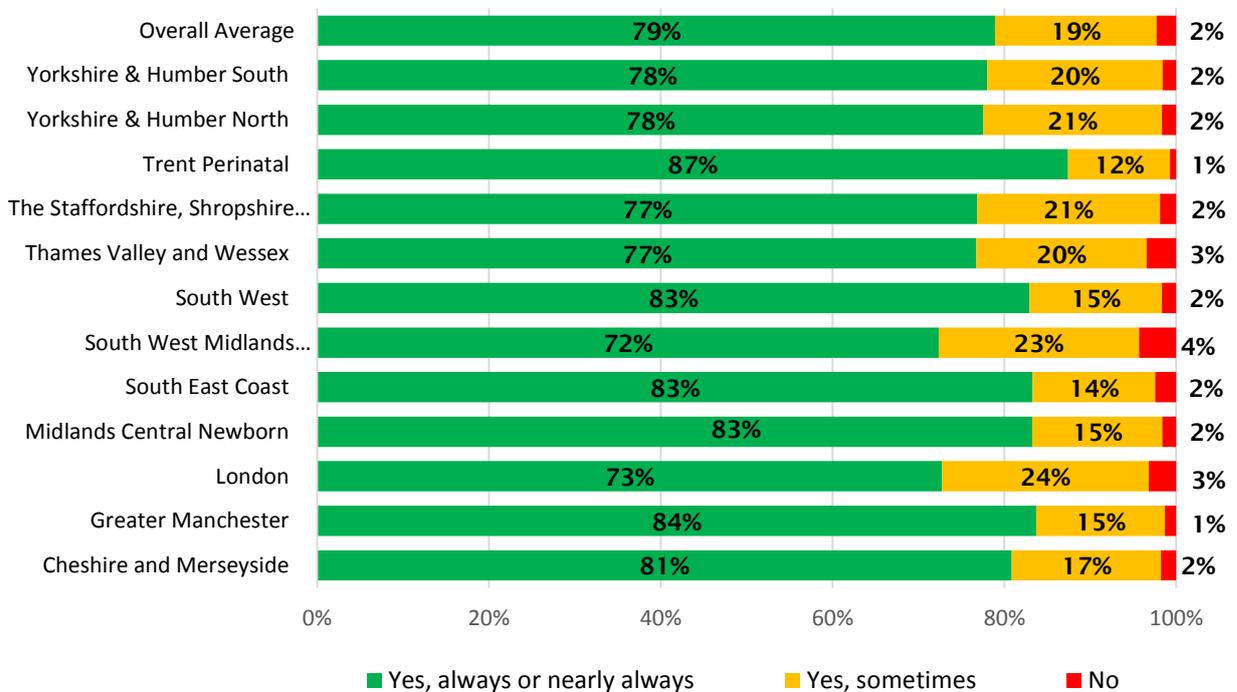
**Graph C4. Were infection control practices explained to you, such as hand washing and procedures for visitors? (Overall n=5820)**



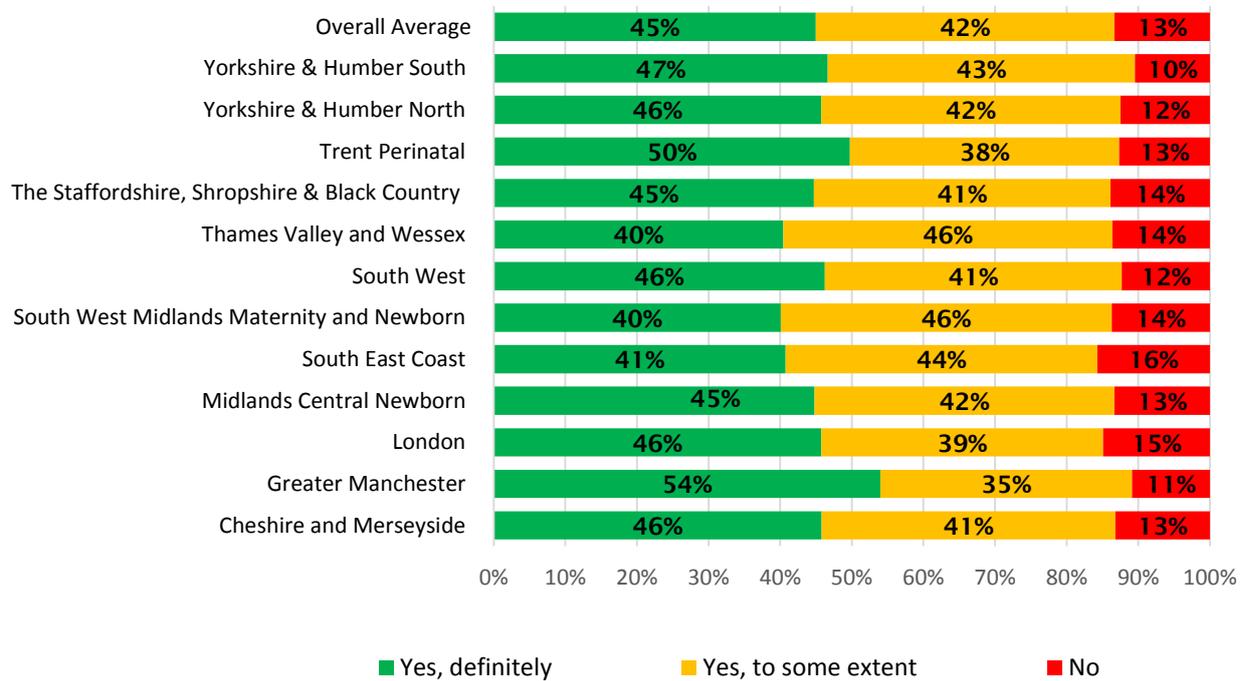
**Graph C5. Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit? (Overall n= 5888)**



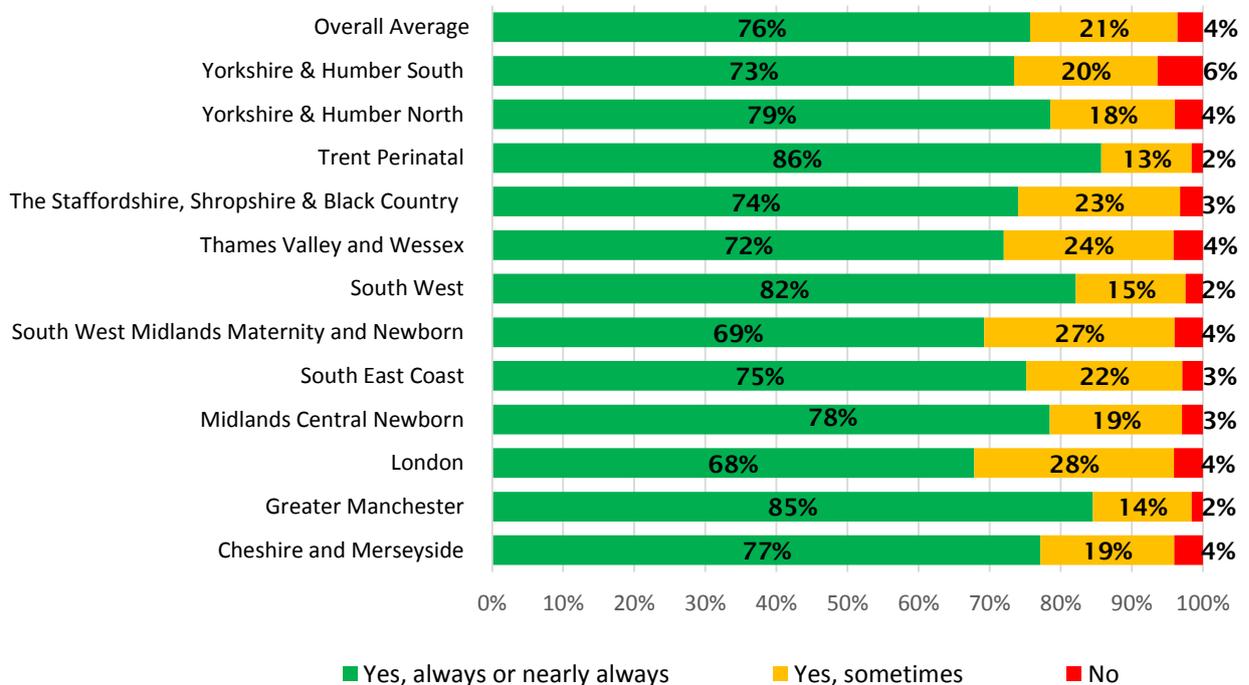
**Graph C6. Were you able to talk to staff on the unit about your worries and concerns? (Overall n=5848)**



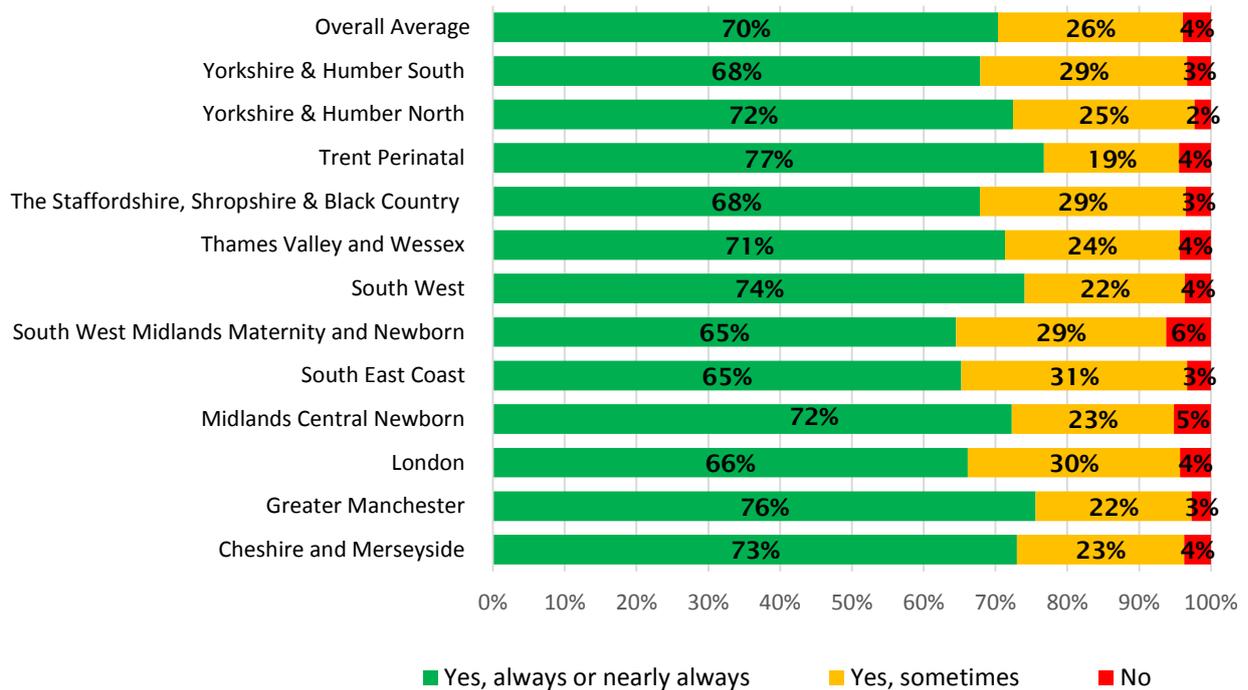
**Graph C7. Were you able to speak to a doctor about your baby as much as you wanted? (Overall n=5687)**



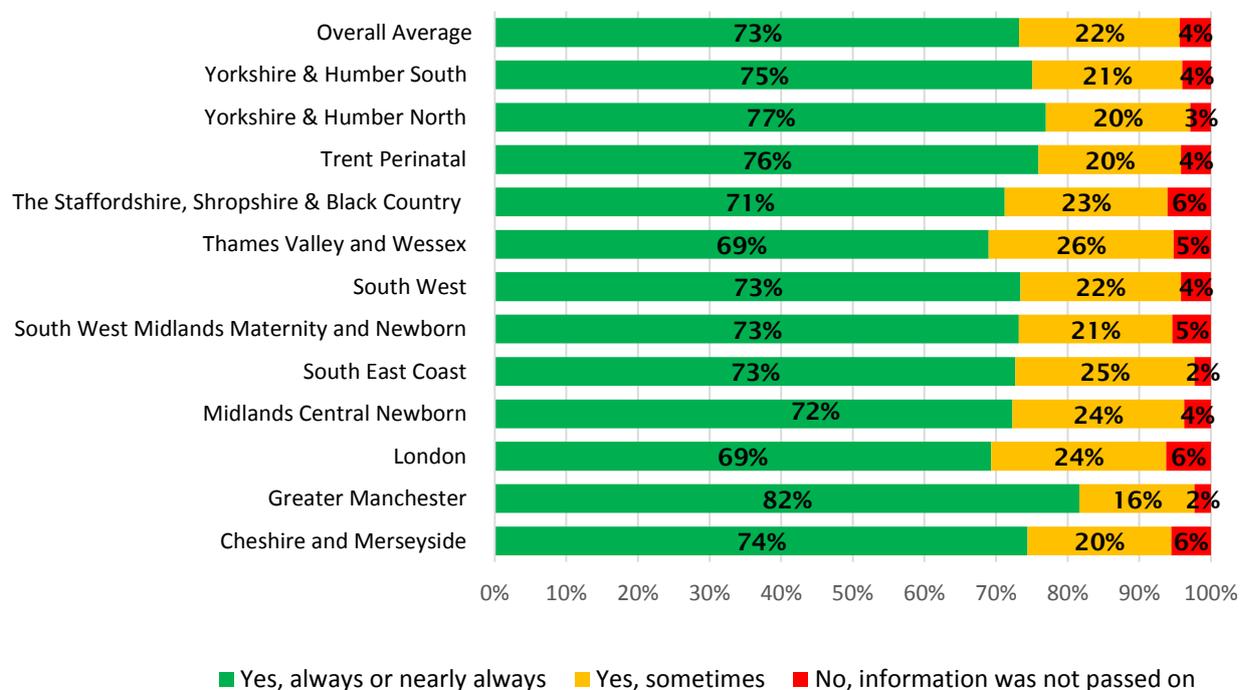
**Graph C8. Were the nurses on the unit sensitive to your emotions and feelings? (Overall n=5786)**



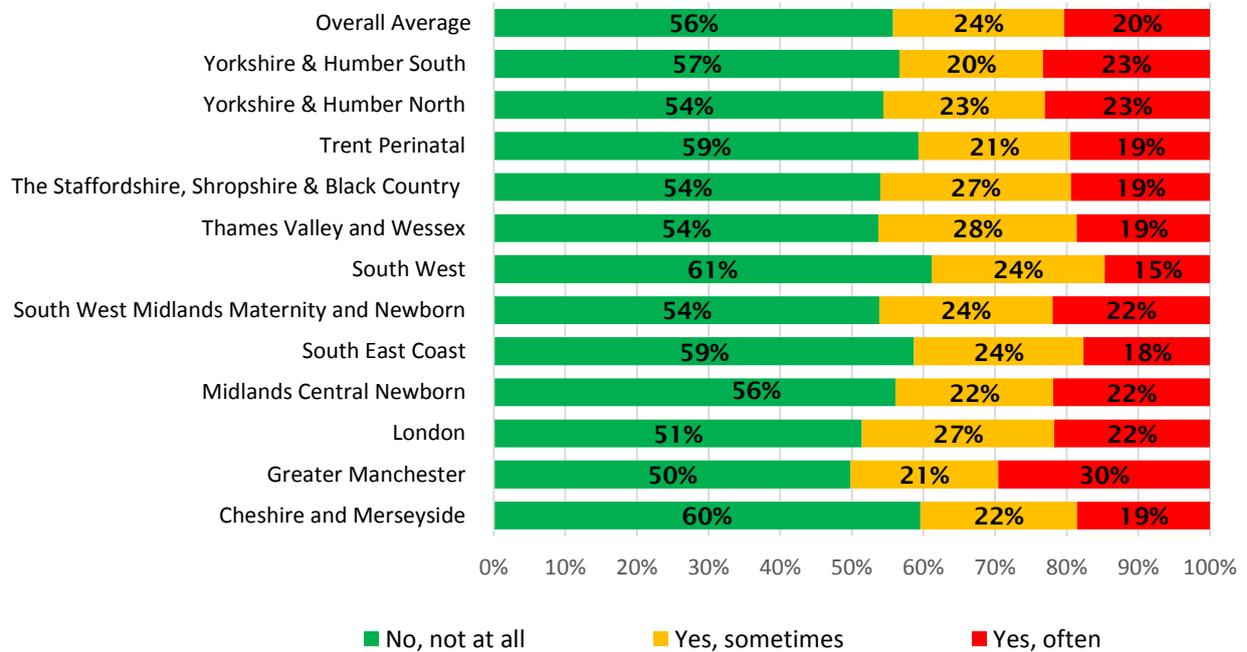
**Graph C9. Were the doctors on the unit sensitive to your emotions and feelings? (Overall n=5365)**



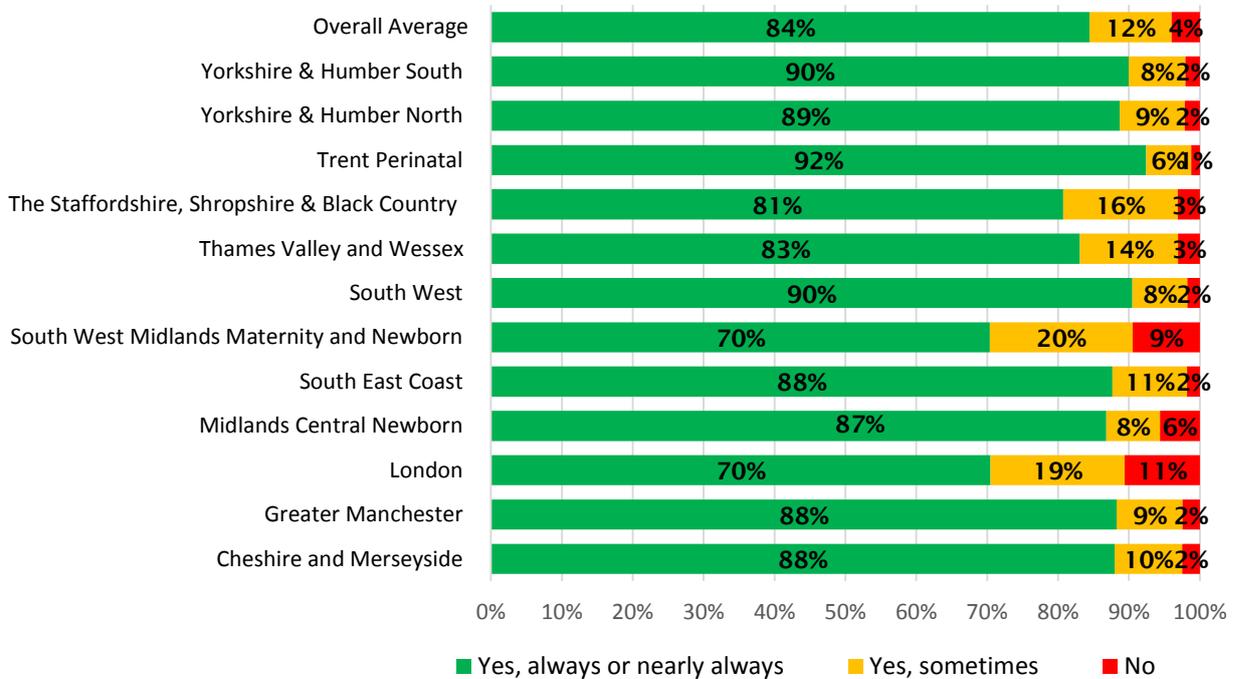
**Graph C10. In your opinion, was important information about your baby passed on from one member of staff to another? (Overall n= 5603)**



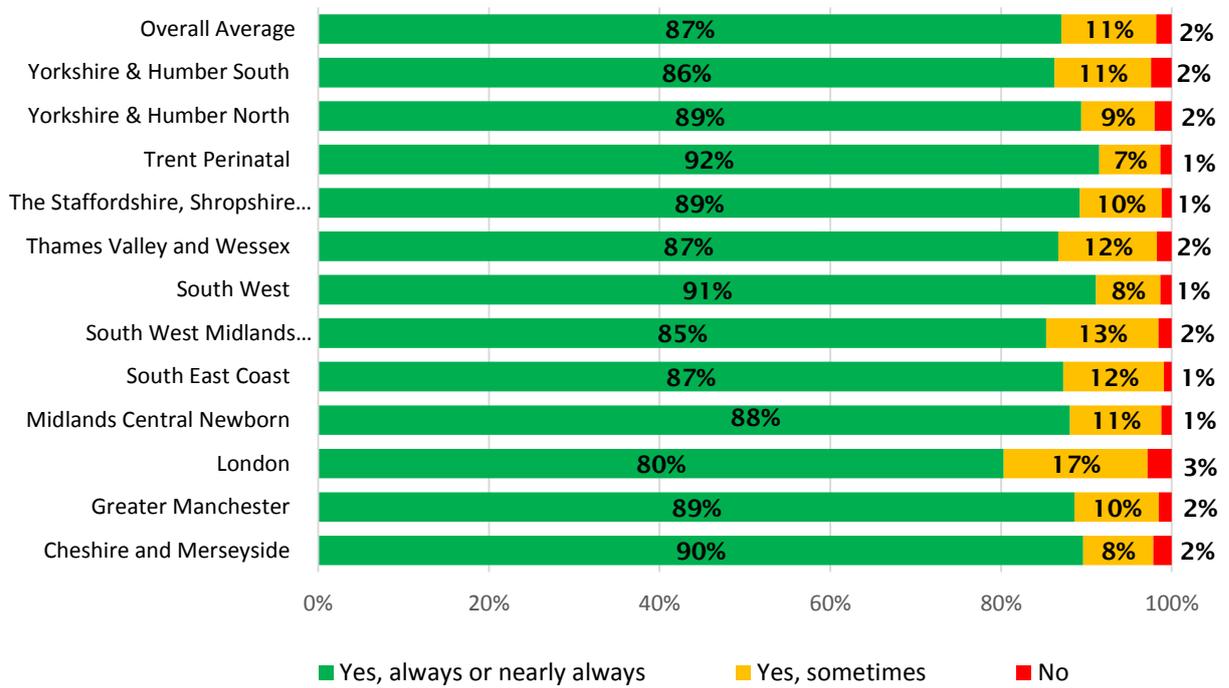
**Graph C11. Did staff give you conflicting information about your baby's condition or care? (Overall n=5868)**



**Graph C12. Did staff refer to your baby by his/her first name? (Overall n=5459)**



Graph C13. Overall, did you have confidence and trust in the staff caring for your baby? (Overall n=5919)



## D. Your involvement in your baby's care

Parents were asked numerous questions about involvement in their baby's care. Figure 5 below maps the proportion of parents who responded positively to questions about being "involved in care" (questions D1 – D7) by network. It highlights the variations between networks for each question in this section. The figure indicates that London network has room for improvement on most questions, particularly with parents being allowed to be present during ward rounds when their baby is being discussed (D5); and arranging the baby's care to fit in with parents usual visiting times (D6).

Figure 6 below presents the proportion of parents who responded positively to questions about "Feeding" (questions D8-D12), by network. Overall, the London, and South West Midlands Maternity and Newborn networks have the most room for improvement compared to other networks. There was the most variation among networks for questions D10-12: whether mothers were given privacy to express milk or breastfeed; receiving support to breastfeed from staff; and receiving support if they used baby formula.

Overall, parents were generally as involved as much they wanted to be in day-to-day care such as nappy changing and feeding, and were told about changes in their baby's condition (see figure 7, graphs D1 and D4). However, over a third of parents (38%, n=2208) stated they were not included in discussions about their baby's care and treatment. Parents from the London network (44%, n=426) and Thames Valley network (43%, n=273) were most likely compared to other trusts to state they were not always included in discussions (see figure 7, graph D3). The London network also had the largest proportion of parents (42%, n=337) compared to other networks who reported they were not always allowed to be present during a ward round when their baby was being discussed (see figure 7, graph D5).

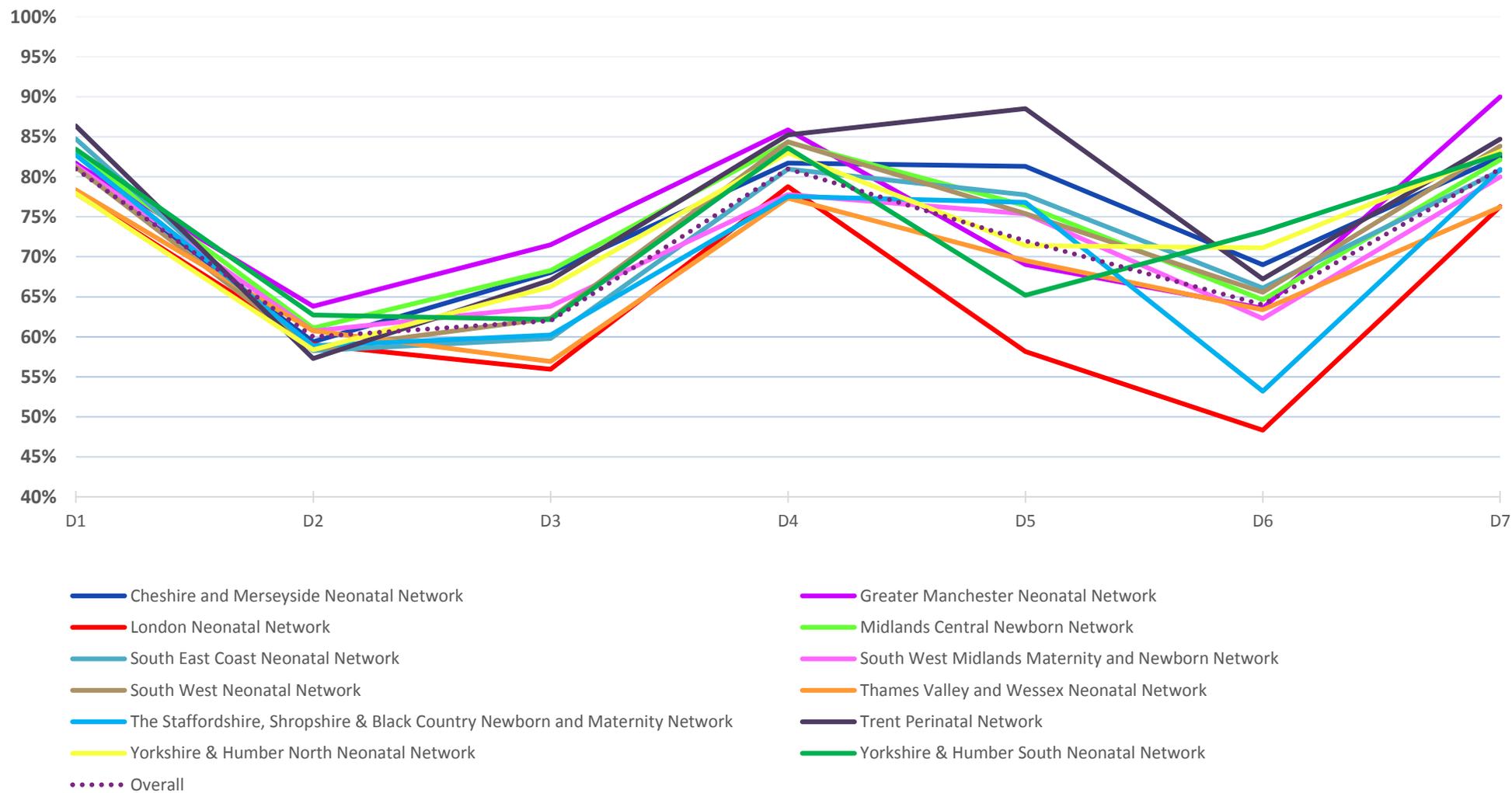
Just over a third of parents did not always feel staff arranged their baby's care to fit in with their usual visiting times (64%, n=2198), and were not able to have as much skin-to-skin contact as they wanted (60%, n=3070). (See figure 7, graphs D6 and D2).

That said, a large proportion of parents (81%, n=4752) stated that staff did help them feel confident in caring for their child (figure 7, graph D7). This is evident in the proportion of parents who felt staff supported them in their choice of feeding. The proportion of parents who felt they fully received the support they needed for the choice of feeding method include:

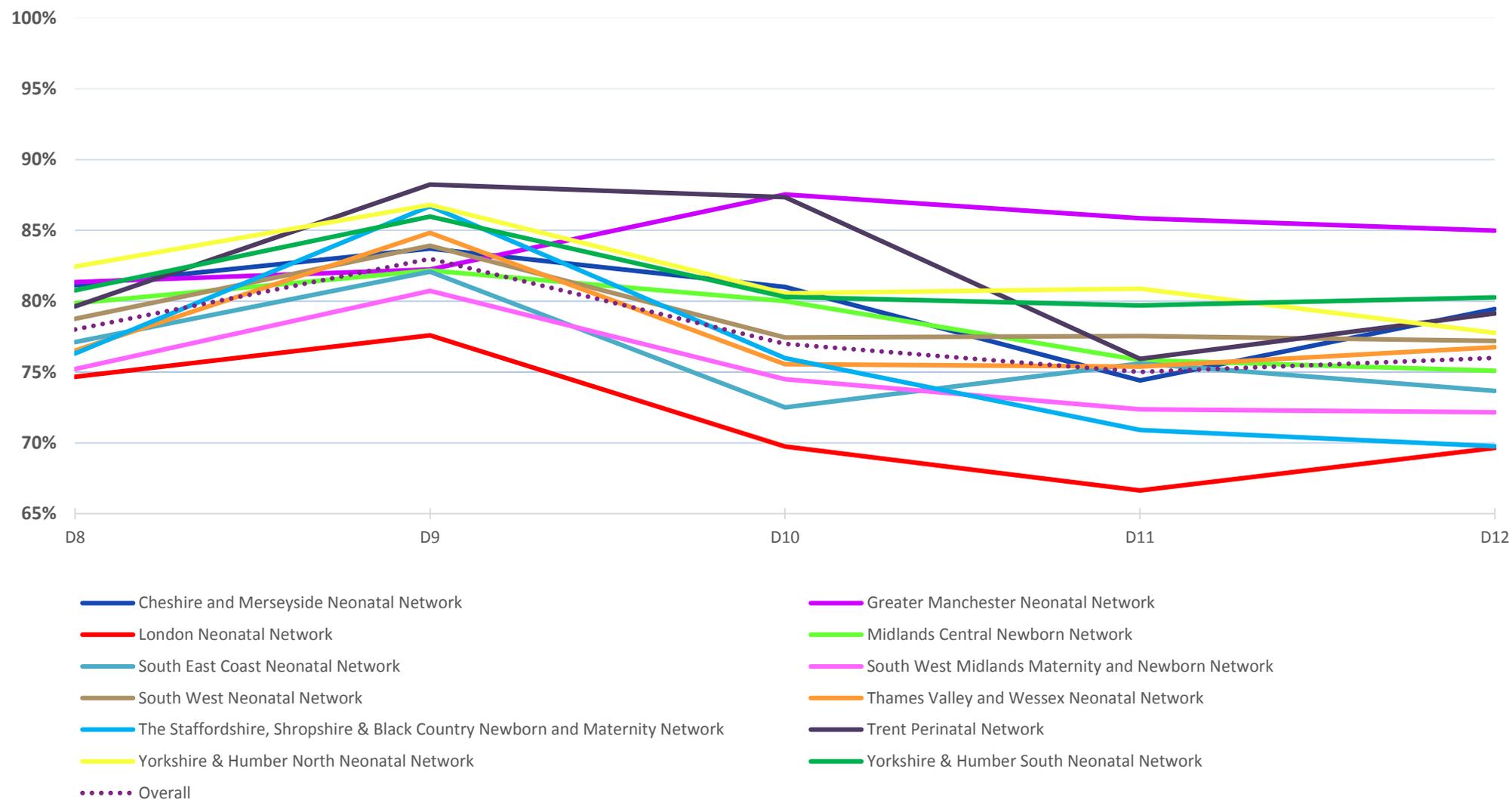
- 78% of n=4735 who wanted and could express milk
- 75% of n=4602 who wanted and could breastfeed
- 76% of n=3507 who wanted to feed their baby formula milk

(See figure 7, graphs D8, D11, & D12).

**Figure 5 - Involvement in care**  
 Proportion of parents who responded positively to questions about being involved in care (D1-D7), by network

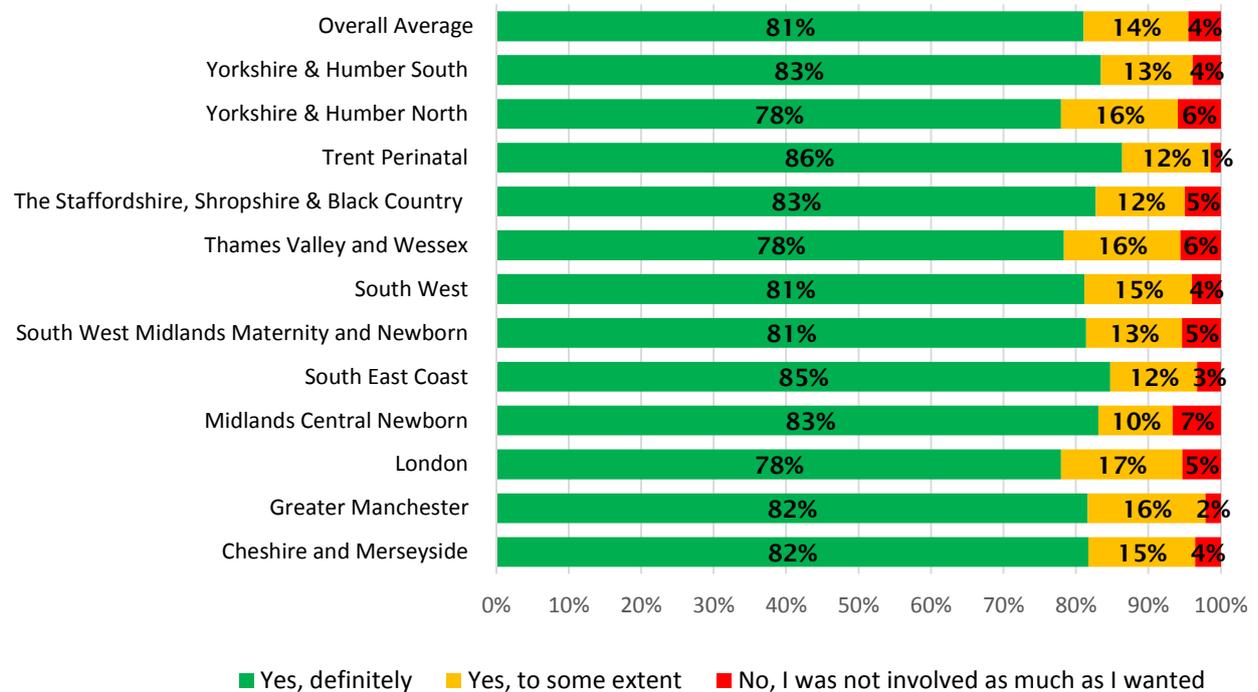


**Figure 6 - Feeding**  
Proportion of parents who responded positively to questions about feeding (D8-D12), by network

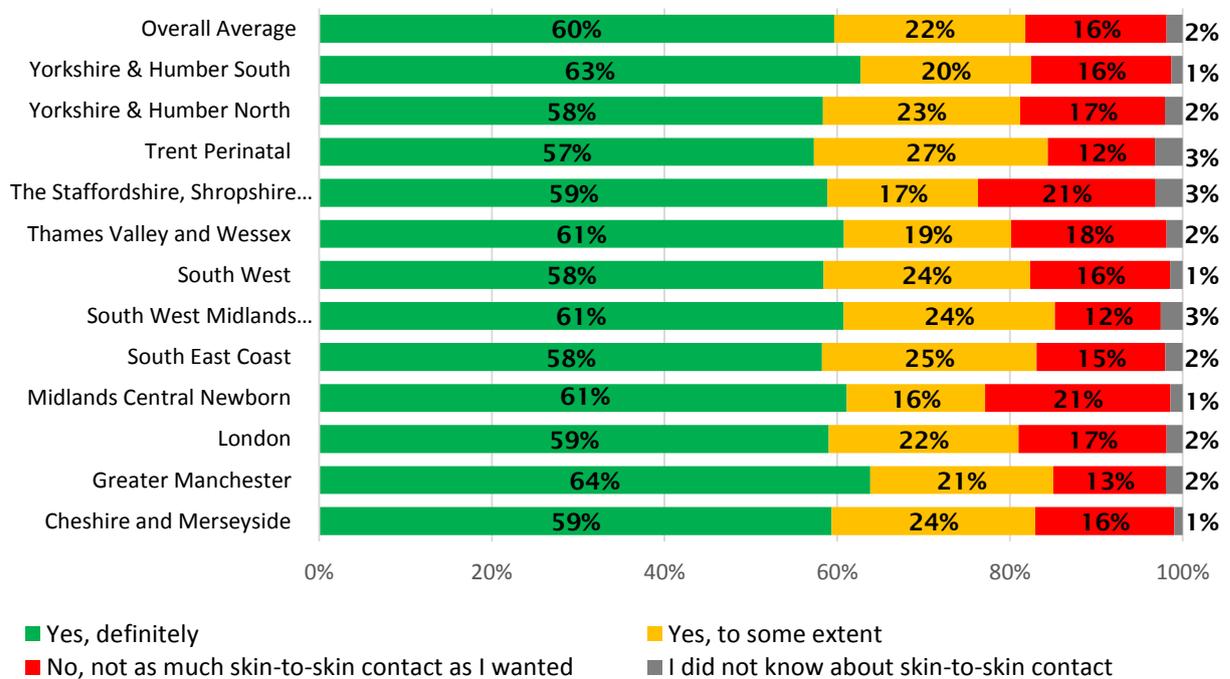


## Figure 7: Section D. Graphs

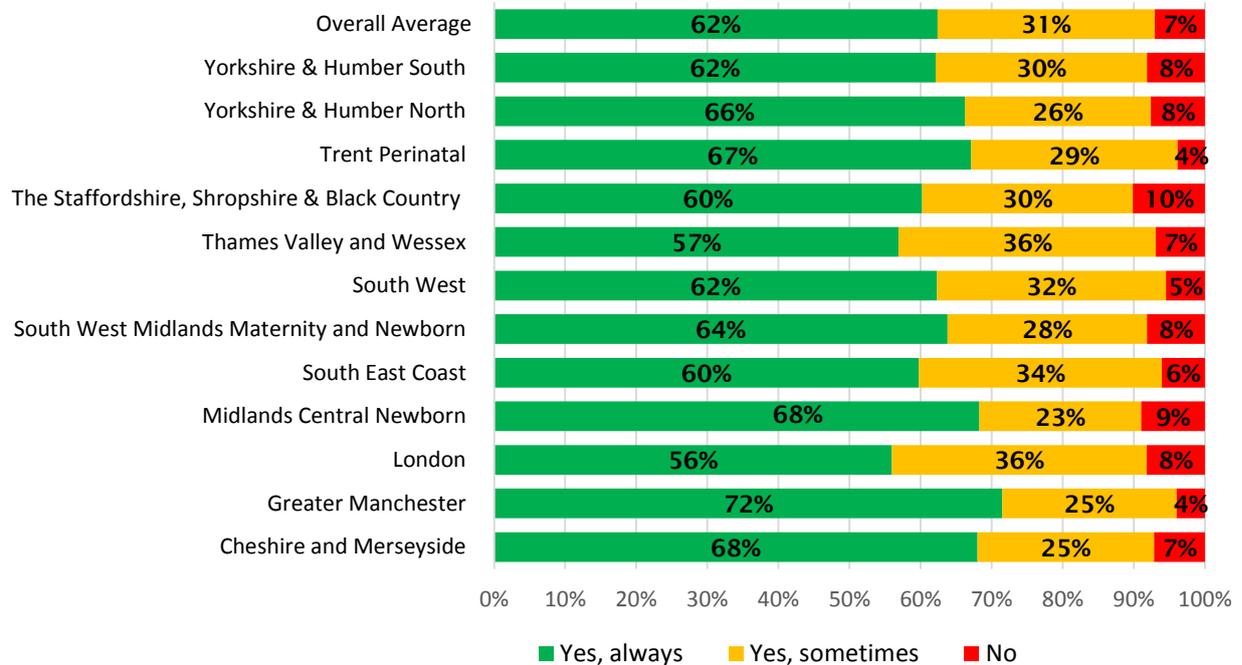
**Graph D1. Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding? (Overall n=5852)**



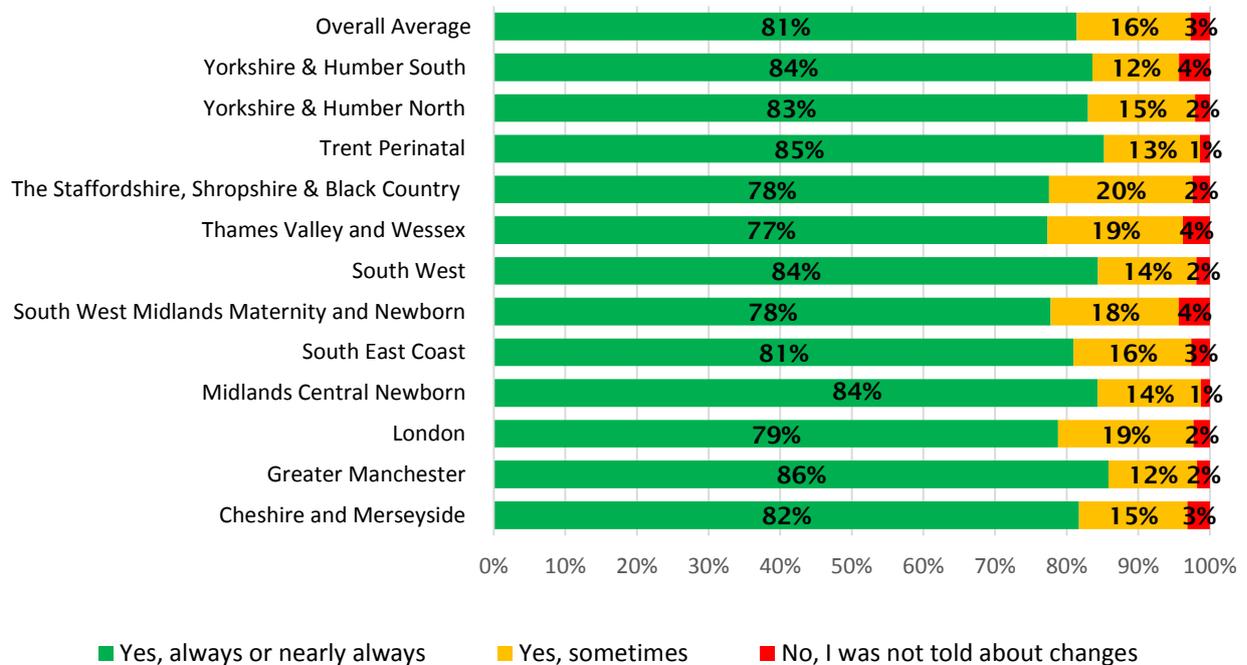
**Graph D2. Did you have as much skin- to-skin contact with your baby as you wanted? (Overall n=5106)**



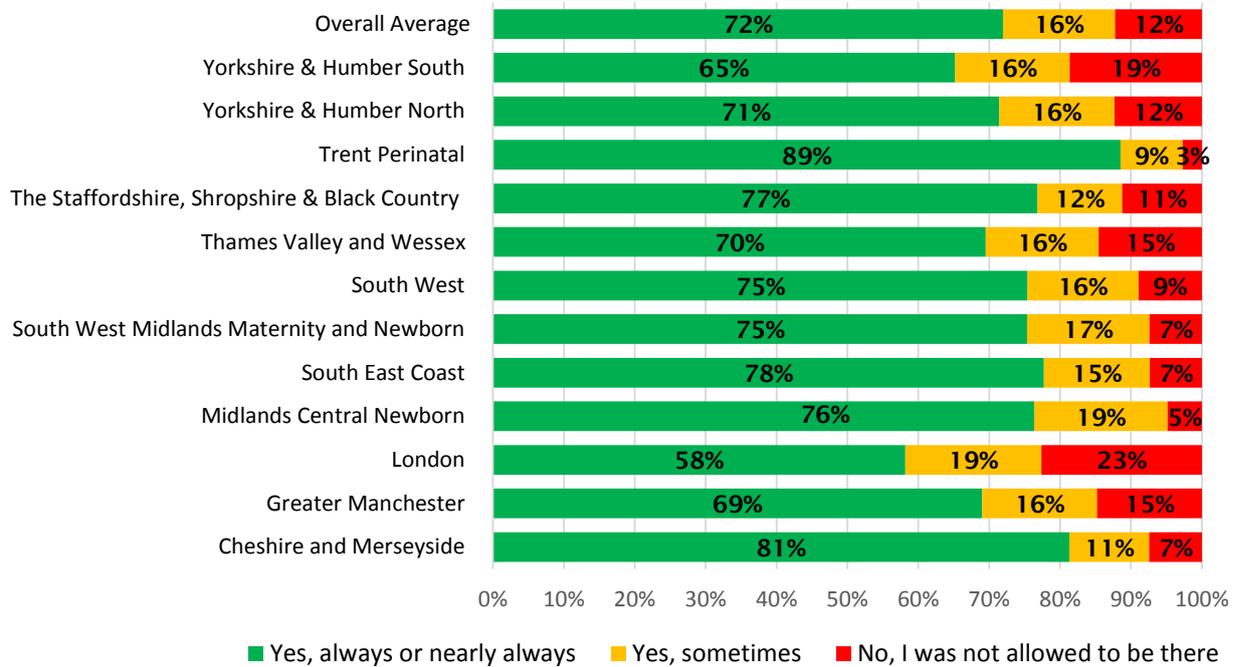
**Graph D3. Did the neonatal staff include you in discussions about your baby's care and treatment?**  
(Overall n=5902)



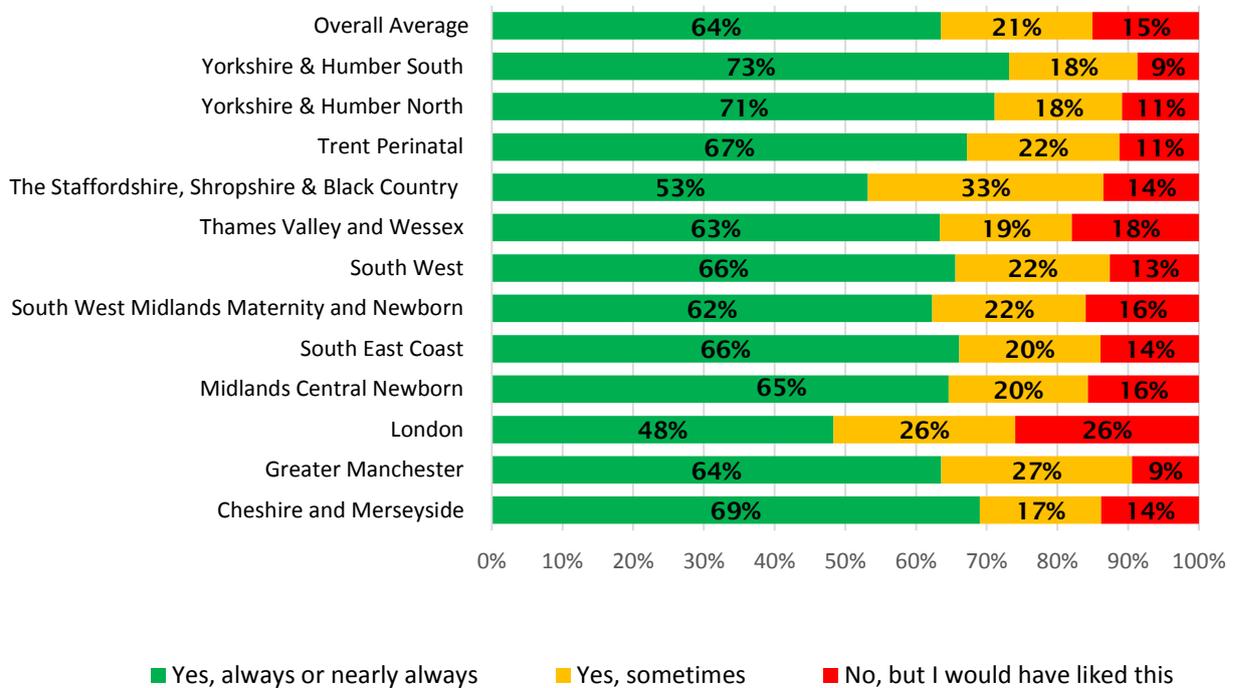
**Graph D4. Were you told about any changes in your baby's condition or care?** (Overall n=5833)



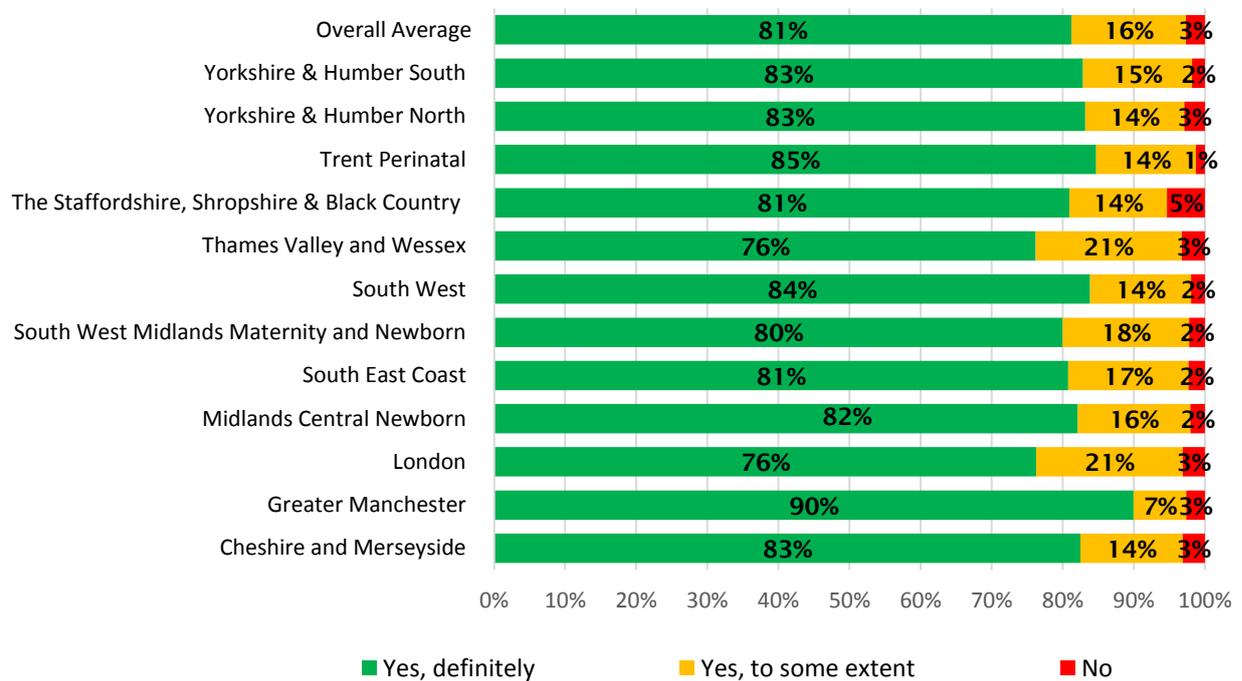
**Graph D5. When a ward round was taking place, were you allowed to be present when your baby was being discussed? (Overall n= 5037)**



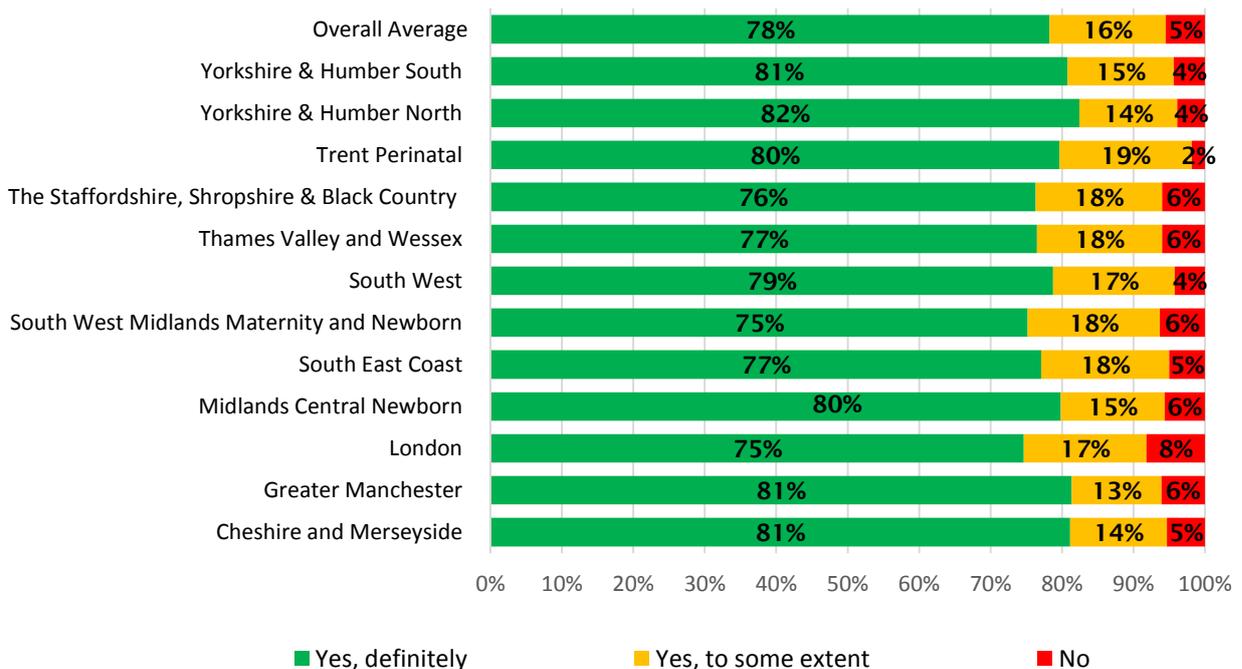
**Graph D6. Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times? (Overall n=5833)**



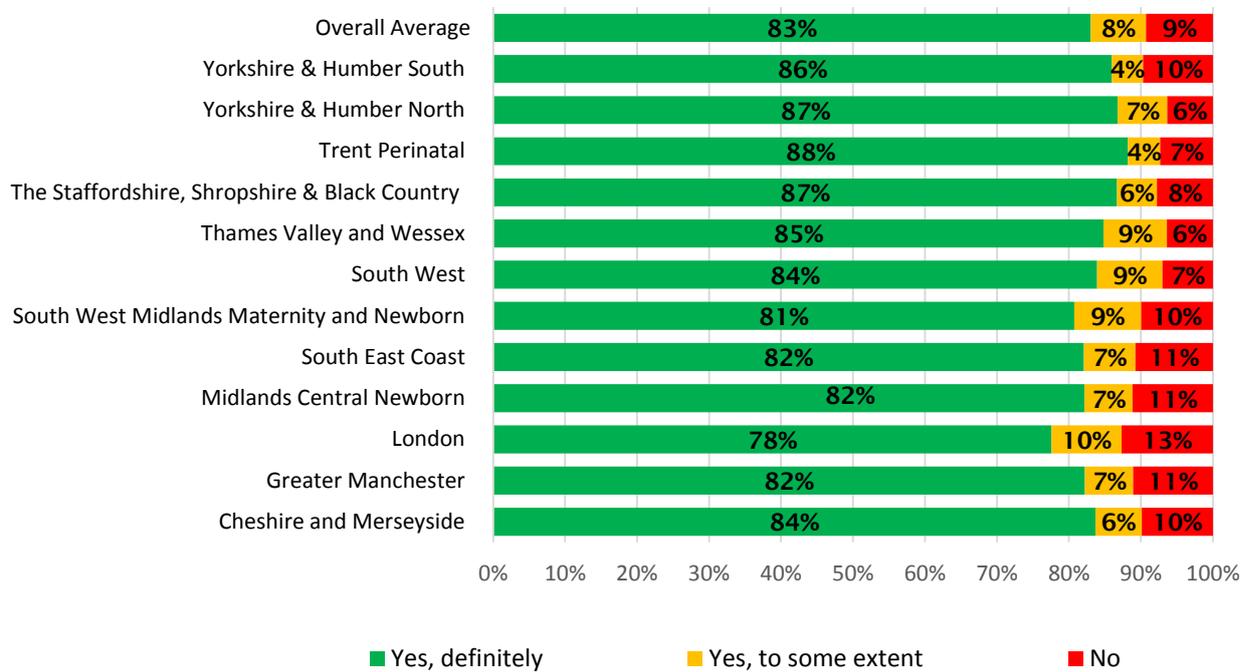
**Graph D7. Overall, did staff help you feel confident in caring for your baby? (Overall n=5876)**



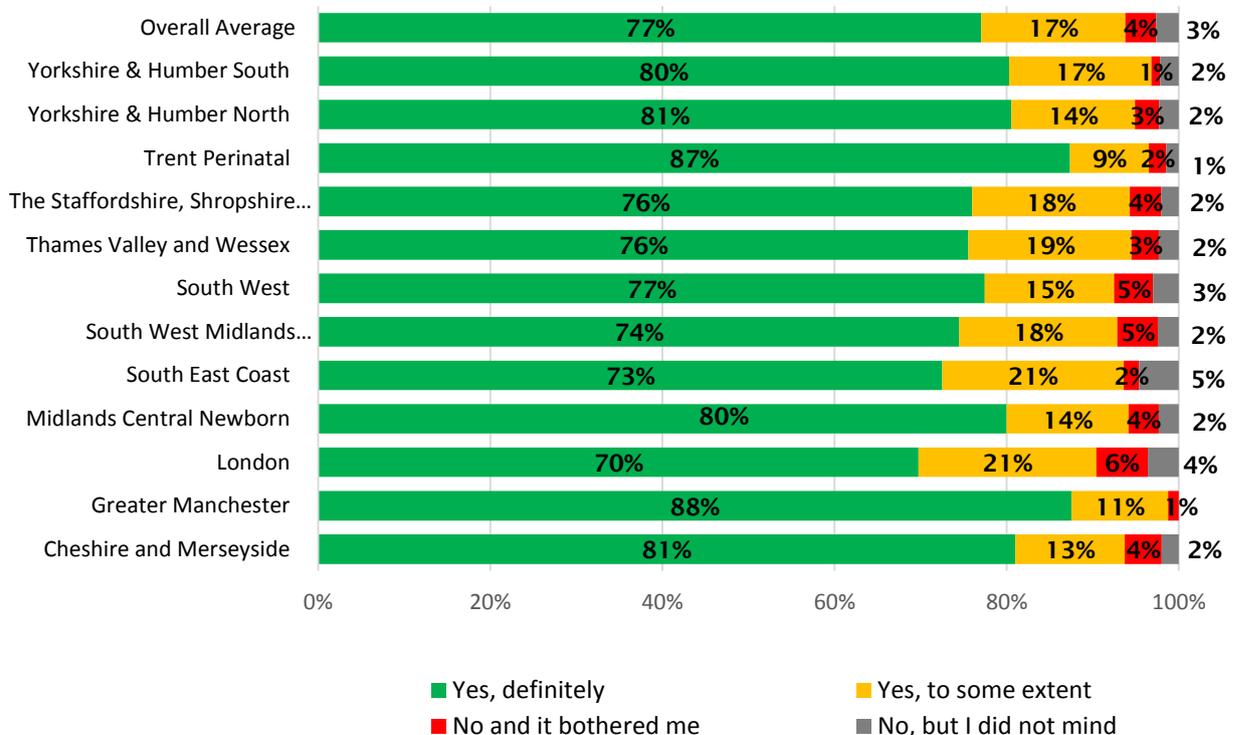
**Graph D8. If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff? (Overall n=4735)**



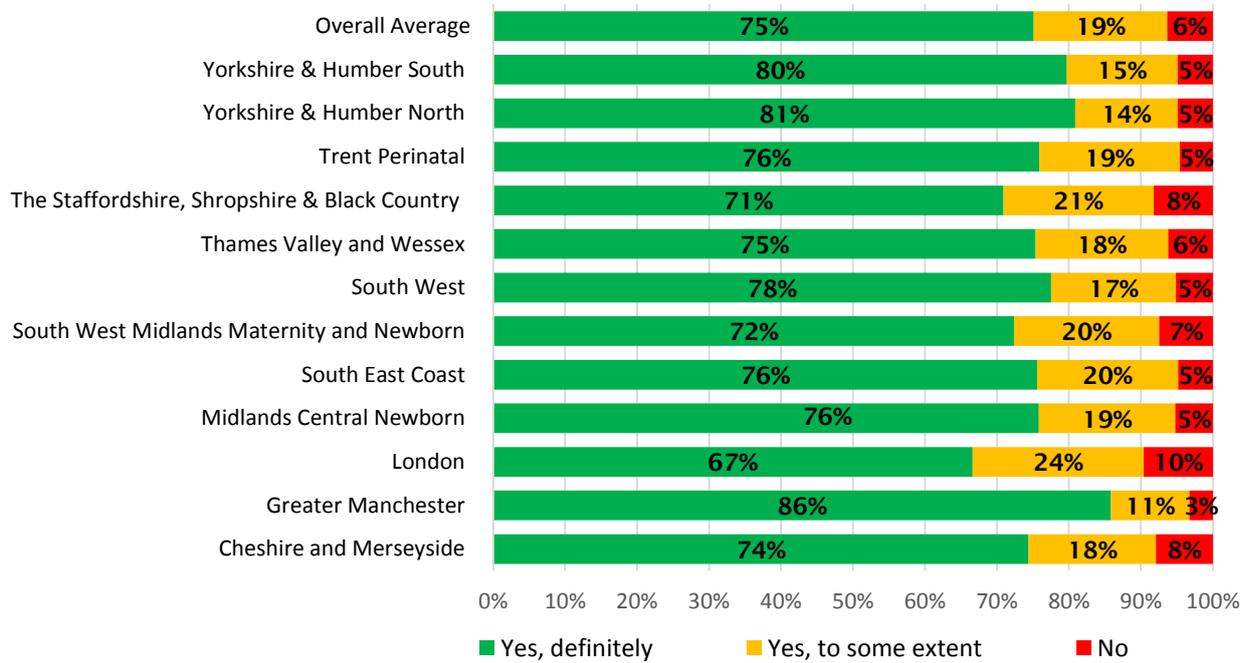
**Graph D9. When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as a breast pump and sterilisation equipment? (Overall n=4721)**



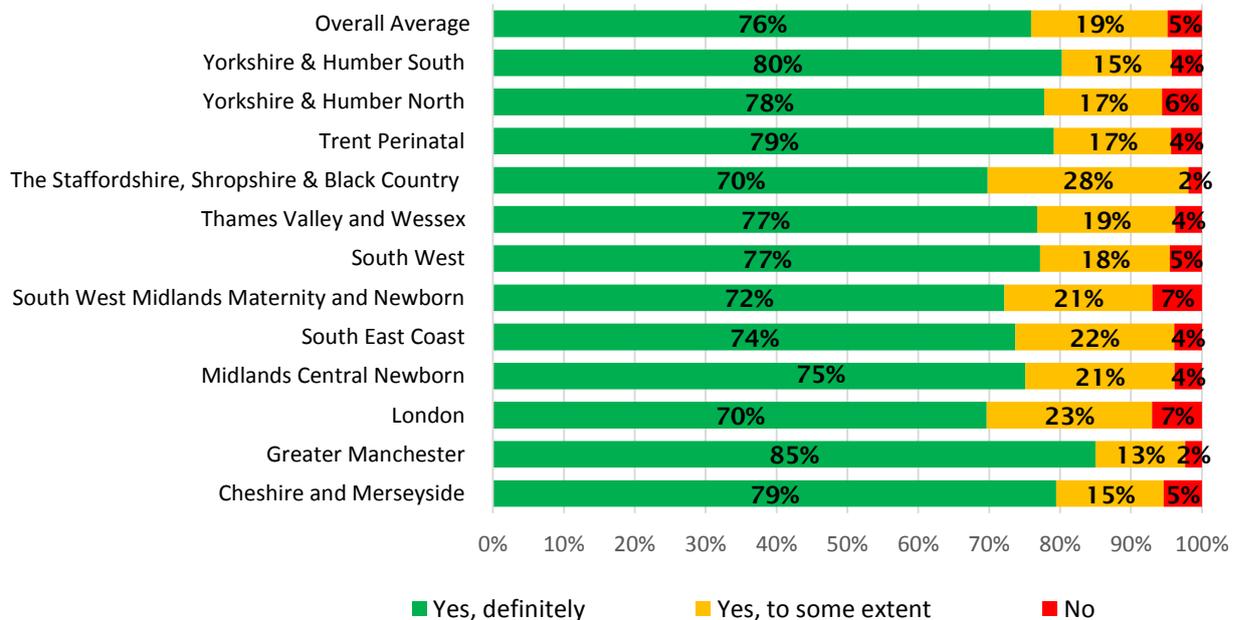
**Graph D10. Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby? (Overall n=4682)**



**Graph D11. If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff? (Overall n=4602)**



**Graph D12. If you fed your baby formula milk, were you given enough support to do this from neonatal staff?**

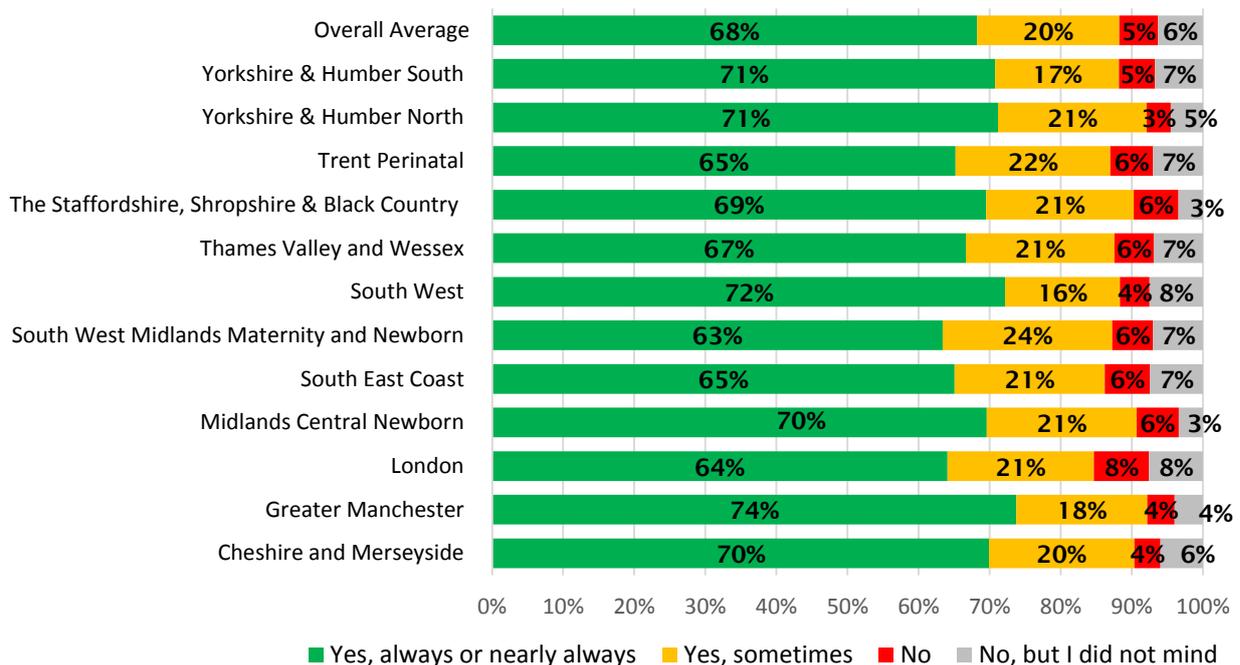


## E. Environment and facilities

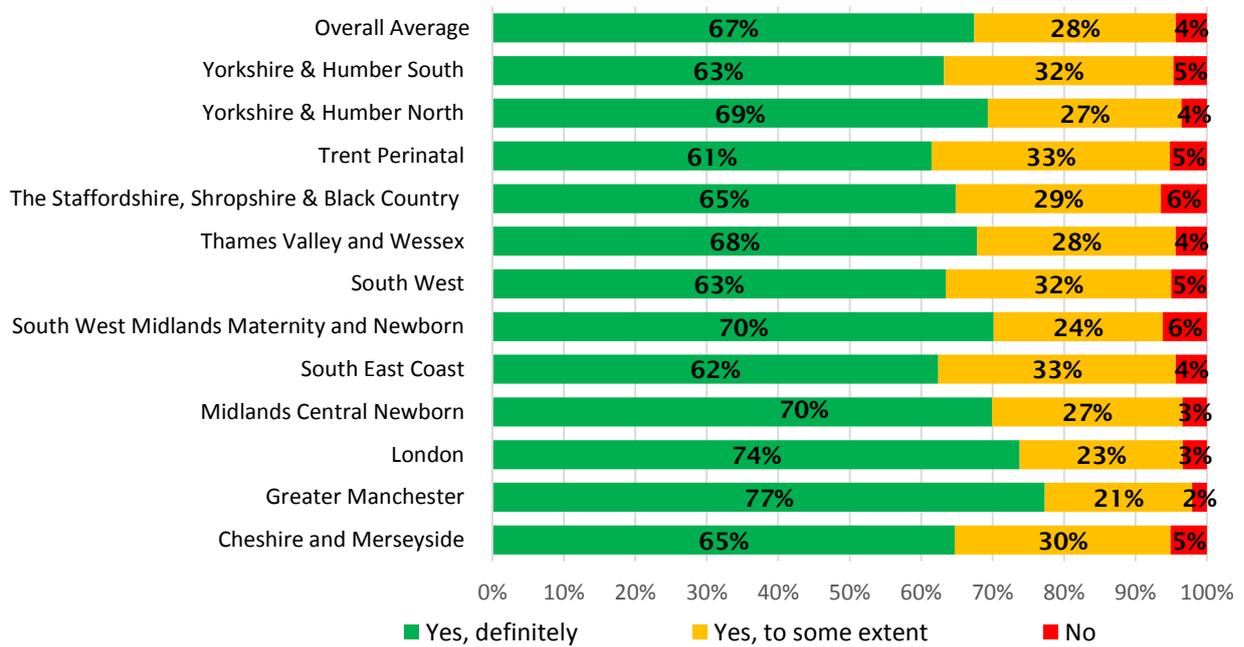
Parents were asked about the facilities and environment of the neonatal unit. Of those respondents who visited their baby, over 90% across all networks felt they were able to visit their baby on the unit as much as they wanted to, with the exception of the London network (86%, n=810) (figure 8, graph E5). There was a similar trend across networks regarding the environment. For most networks, more than two thirds of parents felt they were given enough privacy when discussing their baby’s care with staff on the neonatal unit (68%, n=4026) (figure 8, graph E1), and a large proportion of parents felt there was definitely adequate security on the neonatal unit (80%, n=4708) (figure 8, graph E3). That said, apart from London and Greater Manchester networks, approximately a third of parents stated there was not always enough room to sit alongside their baby’s cot in the unit (32%, n=1886) (figure 8, graph E2). Further, the proportion of parents who were offered accommodation by the hospital who wanted to be close to their baby varied across networks (see figure 8, graph E4).

### Figure 8: Section E. Graphs

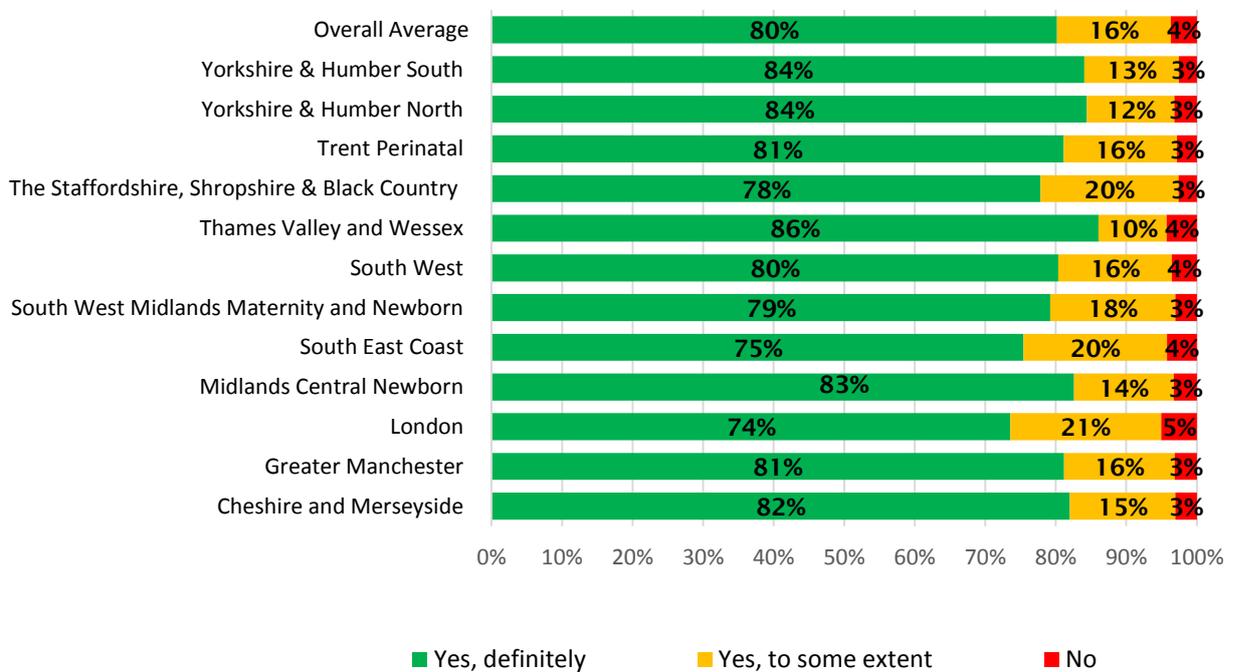
Graph E1. Were you given enough privacy when discussing your baby’s care on the neonatal unit with staff? (Overall n=5502)



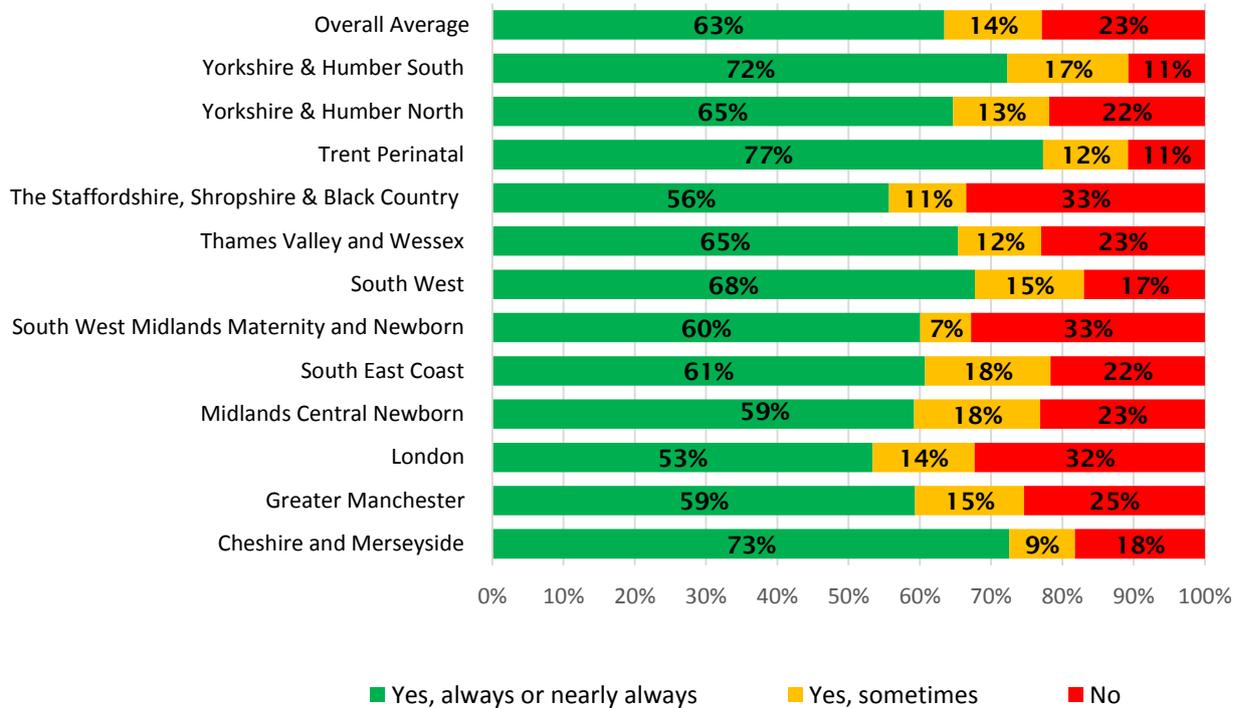
**Graph E2. Was there enough space for you to sit alongside your baby's cot in the unit? (Overall n=5875)**



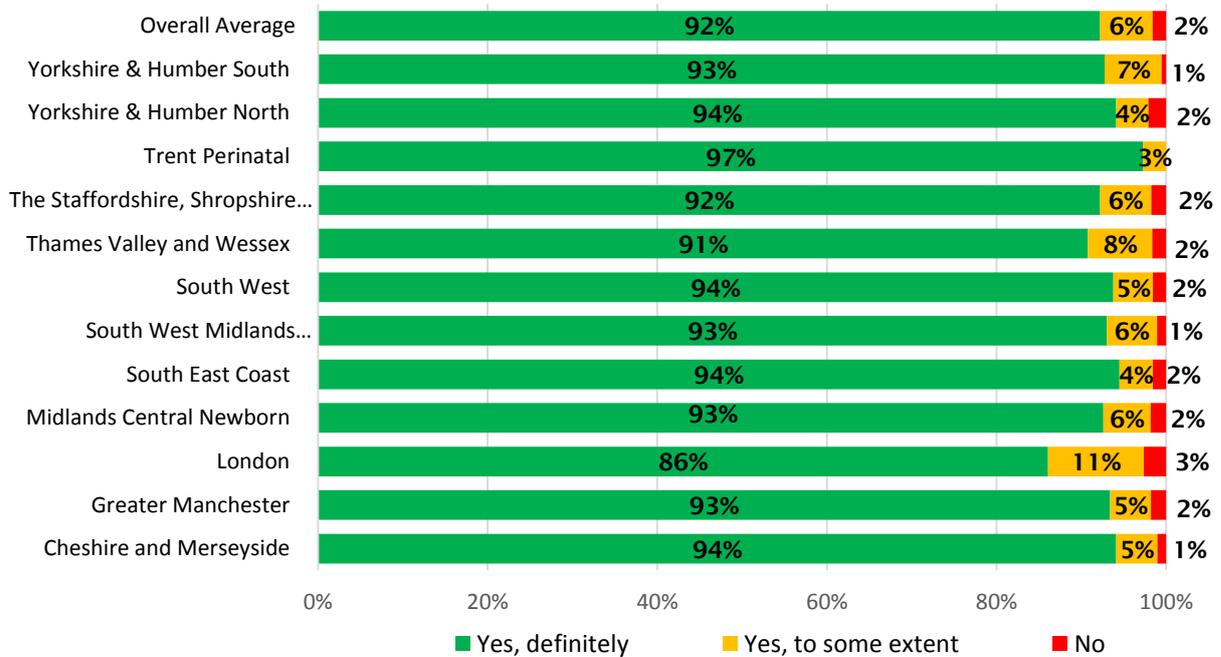
**Graph E3. In your opinion, was there adequate security on the neonatal unit? (Overall n=5894)**



**Graph E4. If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation? (Overall n=4538)**



**Graph E5. Were you able to visit your baby on the unit as much as you wanted to? (Overall n=5840)**



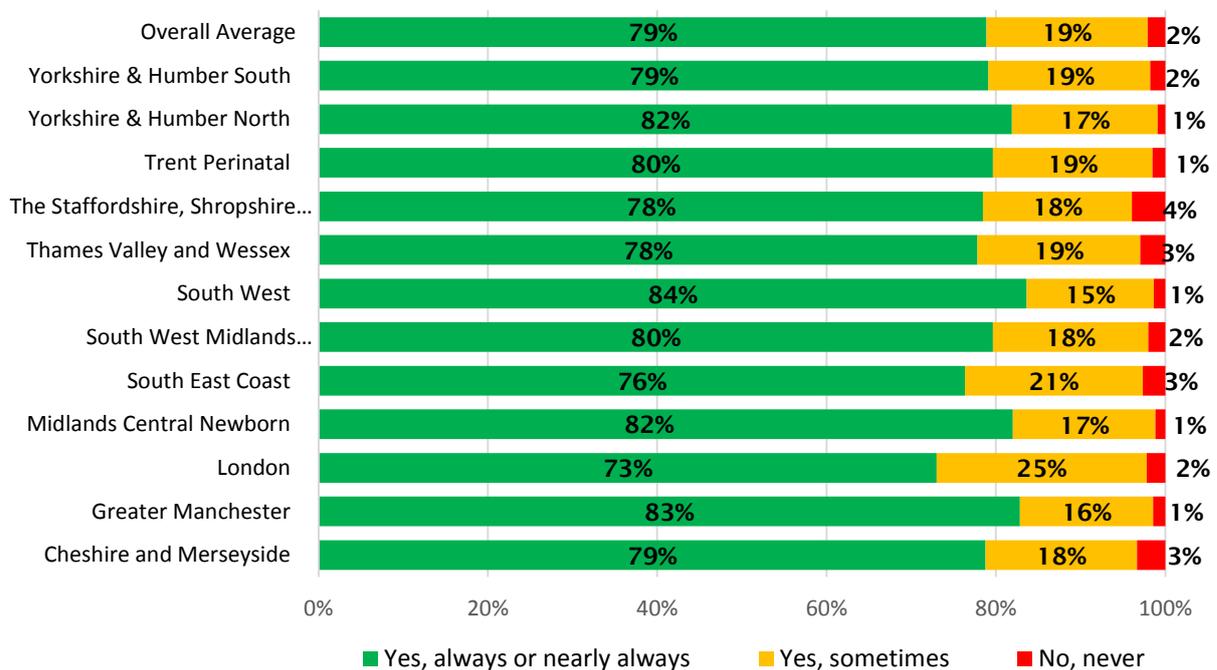
## F. Information and support for parents

Overall, the majority of parents from all networks felt they always or sometimes received answers they could understand to their questions about their baby’s condition and treatment (see figure 9, graph F1). That said, there is room for improvement for all networks to provide written information to assist parents with understanding their baby’s condition and treatment. The London, South East Coast, and Staffordshire, Shropshire and Black Country networks, have the most room for improvement where 42% of parents stated they did not receive any or enough written information (see figure 9, graph F2).

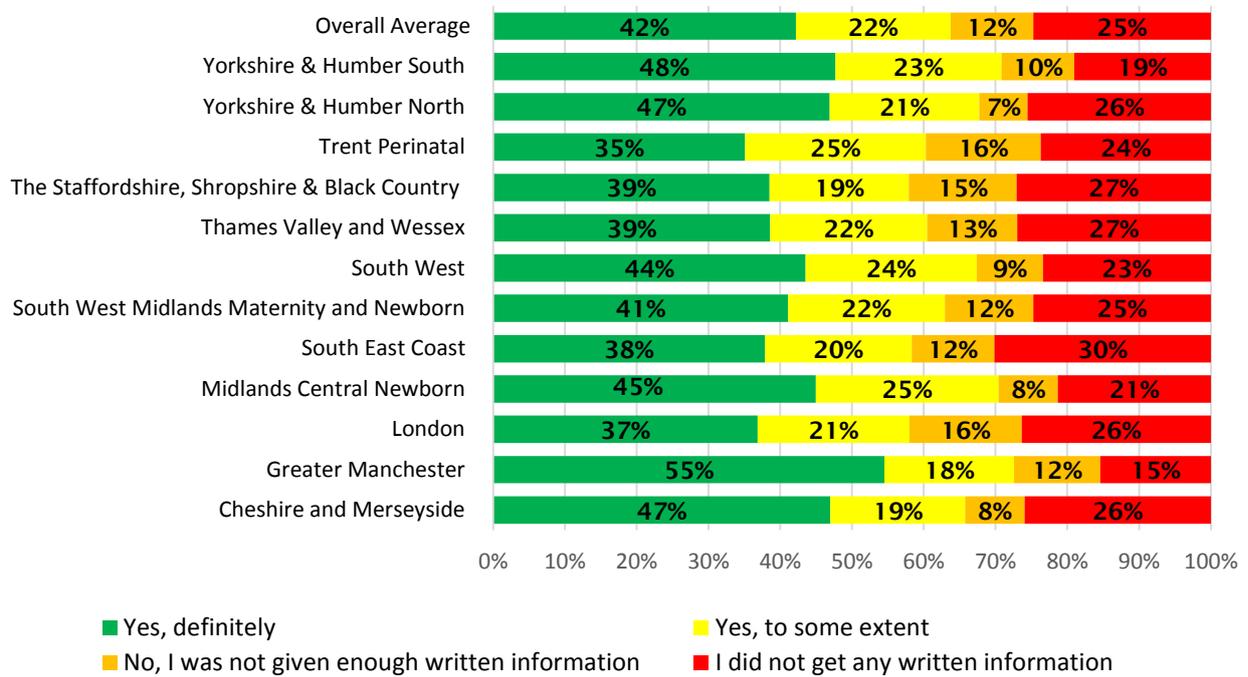
Almost three quarters of parents (71%, n=3336) who wanted or needed it, did not always receive information about help they could get with expenses related to their baby’s stay in the neonatal unit, or about support groups such as Bliss (64%, n=3292). Parents from South West Midlands Maternity and Newborn (17%, n=45), and South East Coast networks (19%, n=85) were least likely to receive information about expenses, compared to other networks (see figure 9, graph F5). Parents from Greater Manchester were slightly less likely than parents from other networks to state they received information about support groups (30%, n=94) (see figure 9, graph F6).

### Figure 9. Section F. Graphs

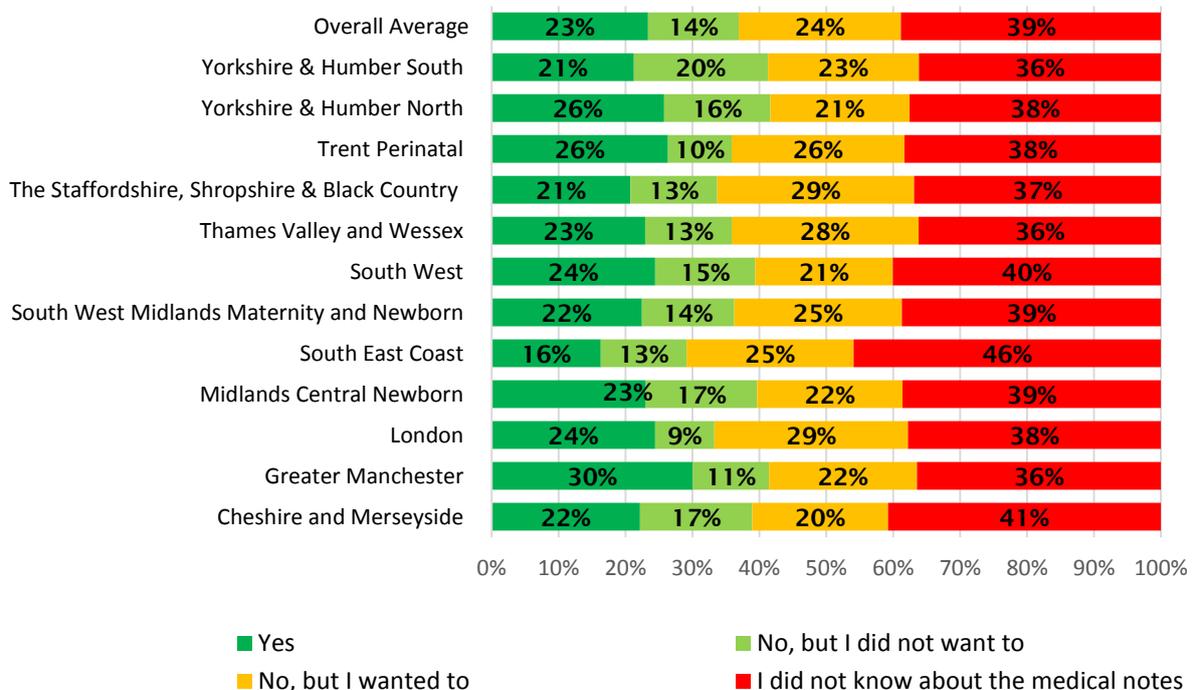
Graph F1. If you asked questions about your baby’s condition and treatment, did you get answers you could understand? (Overall n=5898)



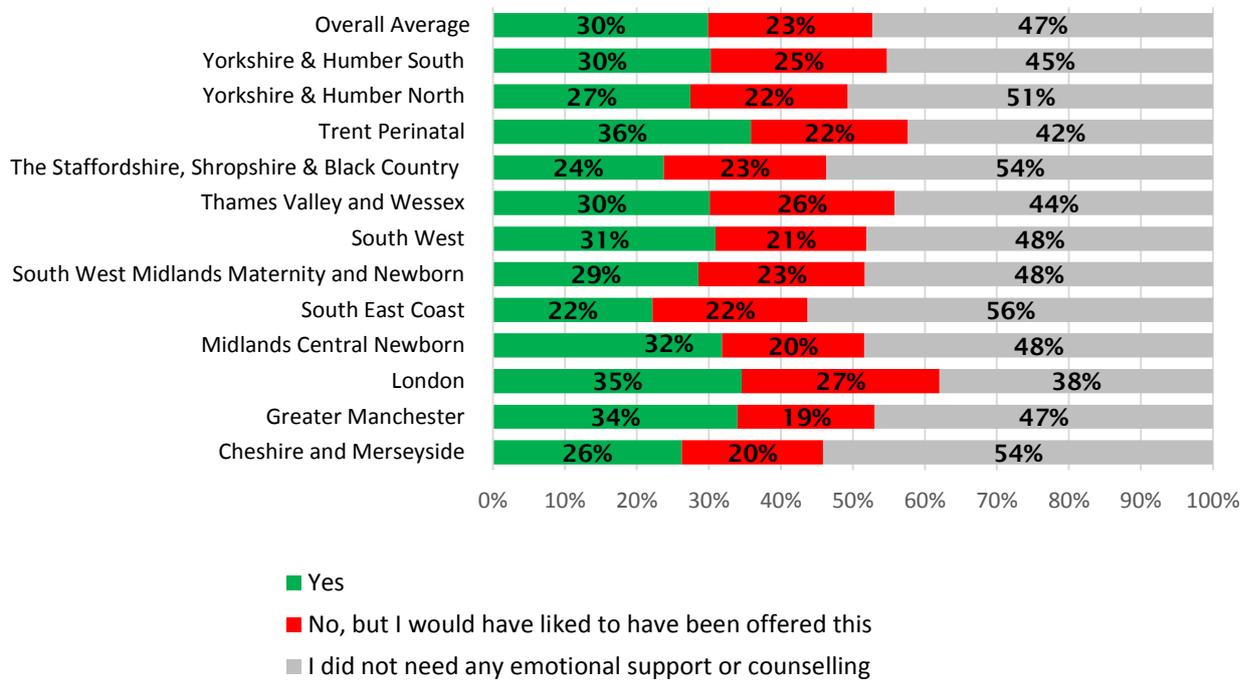
**Graph F2. Were you given enough written information to help you understand your baby's condition and treatment? (Overall n=5251)**



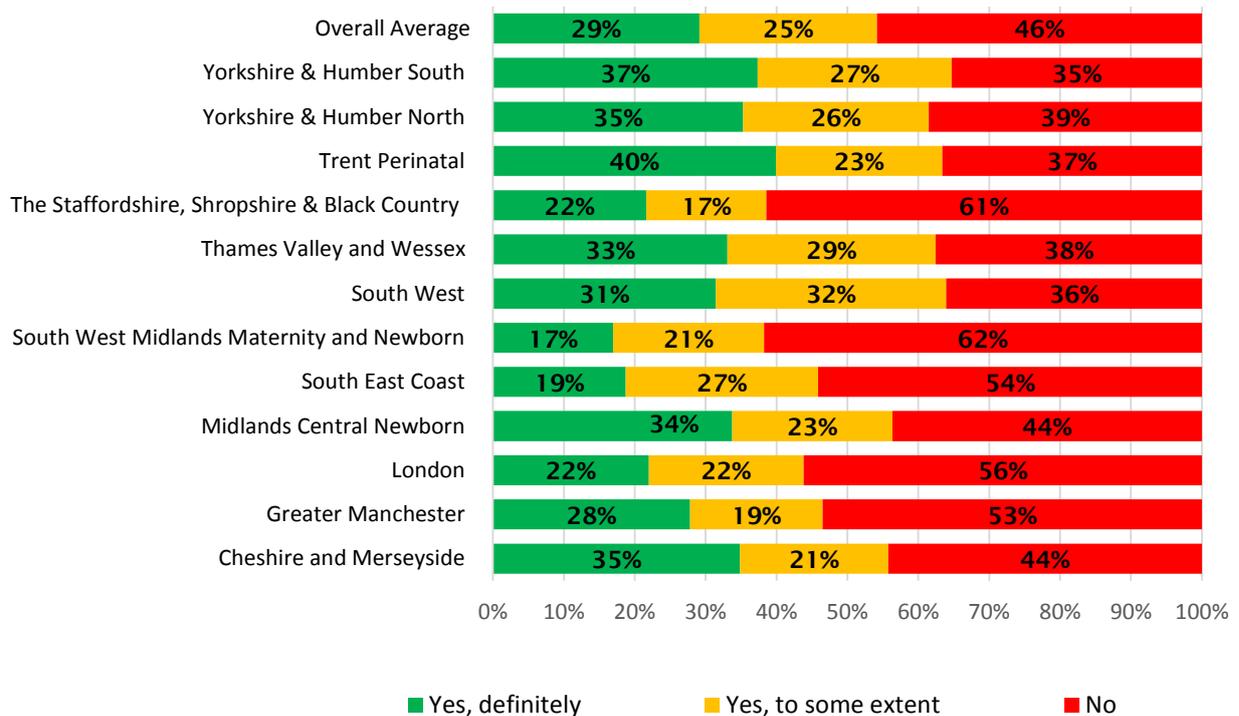
**Graph F3. Did you have an opportunity to go through your baby's medical notes with staff while they were in the neonatal unit?**



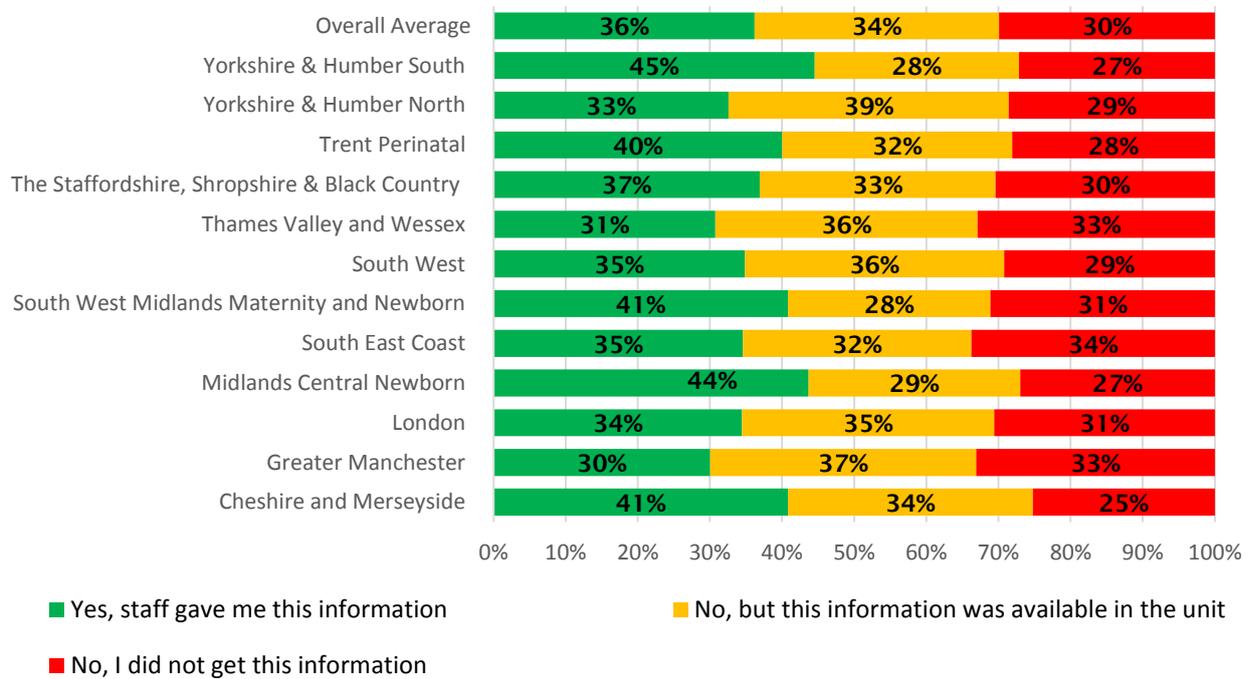
**Graph F4. Were you offered emotional support or counselling services from neonatal unit staff? (Overall n=5856)**



**Graph F5. Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit? (Overall n=4709)**



**Graph F6. Did staff give you any information about parent support groups, such as Bliss or other local groups? (Overall n=5153)**



## G. Leaving the neonatal unit

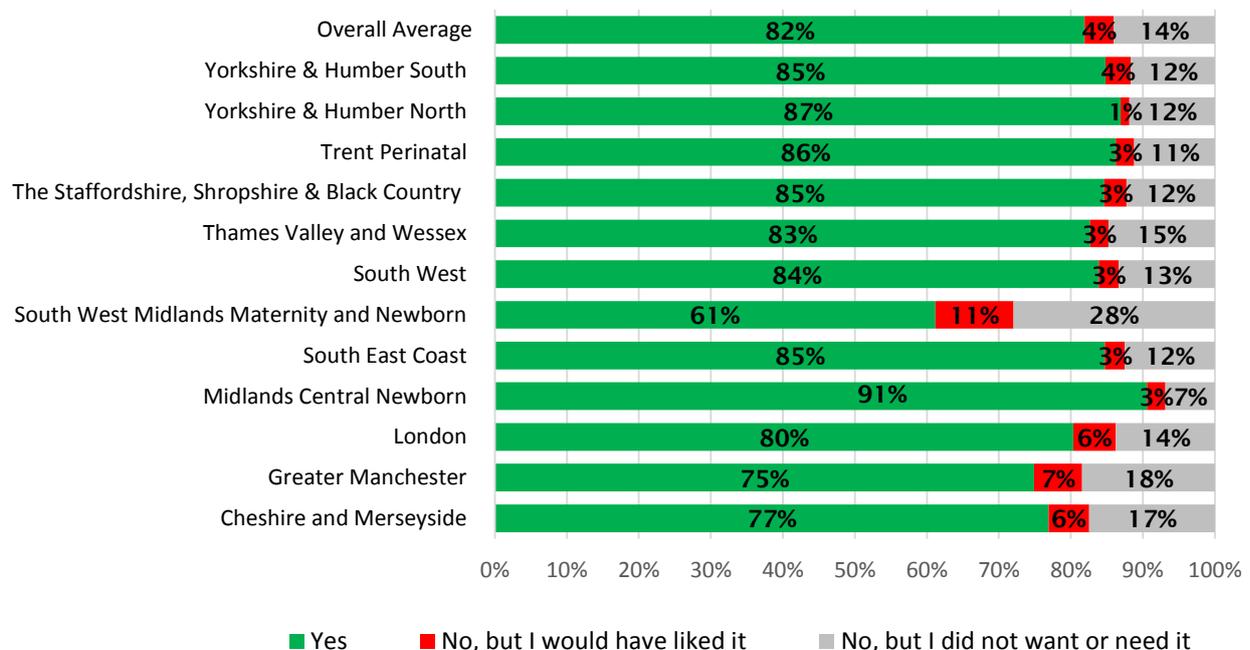
Parents were asked questions about leaving the neonatal unit when their baby was discharged. Overall, the majority of parents whose baby went home after discharge stated they were offered overnight accommodation at the hospital before they left the neonatal unit (82%, n=2991). However, parents from South West Midlands (61%, n=87) were least likely compared to other networks to state they were offered, but also had the highest proportion who said they did not want or need this (28%, n=42) (figure 10, graph G3).

Overall, three quarters of parents (75%; n=4427) stated they felt prepared for their baby's discharge from the neonatal network, with those from Midlands Central Newborn Network most likely compared to other networks to note they felt prepared (84%, n=282) (see figure 10, graph G4). That said, more than a third of parents said they did not fully receive enough information on what to expect in terms of their baby's progress and recovery (38%, n=2245) (See figure 10, graph G5).

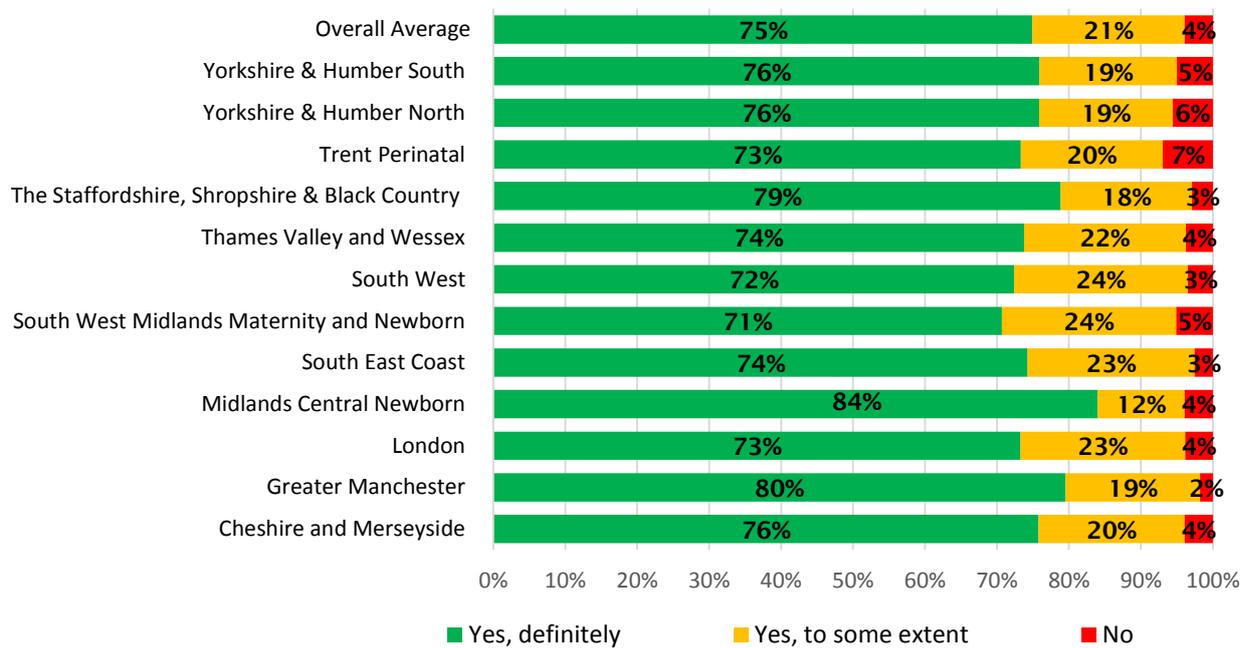
Finally, overall 76% (n=4452) of parents said it is extremely likely they would recommend the neonatal unit to friends and family if their baby needed similar care or treatment. The London network however has the most room for improvement overall compared to other networks with 69% (n=648) of parents saying it is extremely like they would recommend units in this network. Please refer to figure 10, graph G6 for a full breakdown of this question by network.

### Figure 10: Section G. Graphs

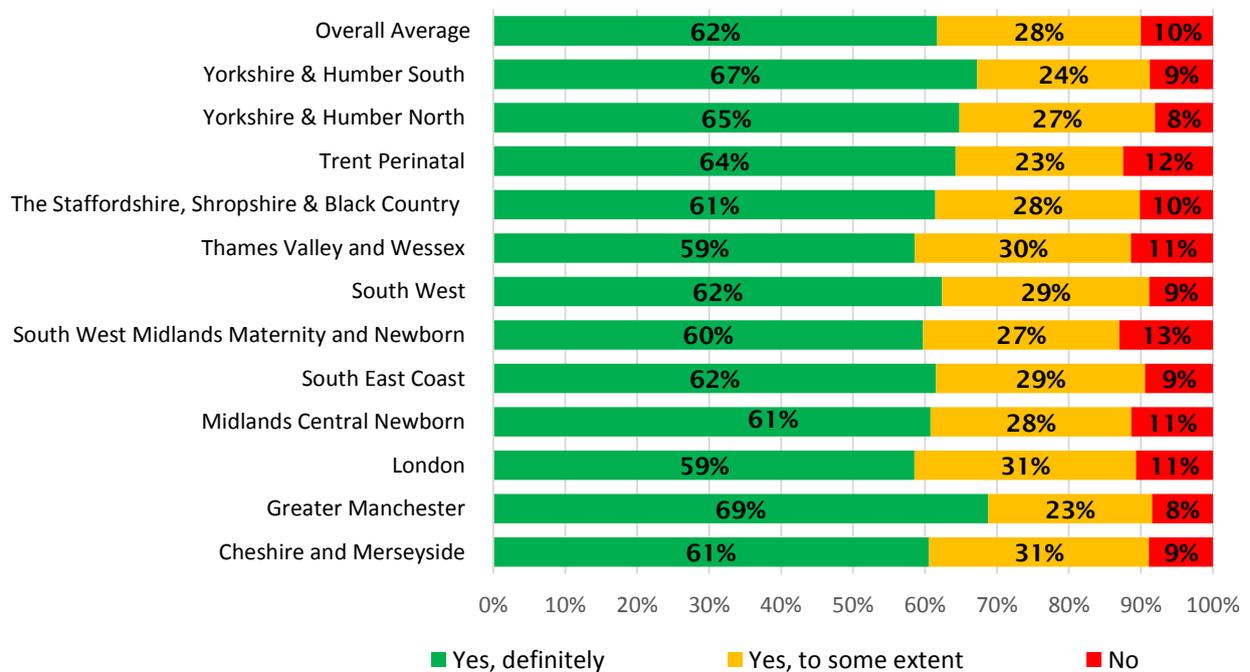
**Graph G3. Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit? (Overall n=3629)**



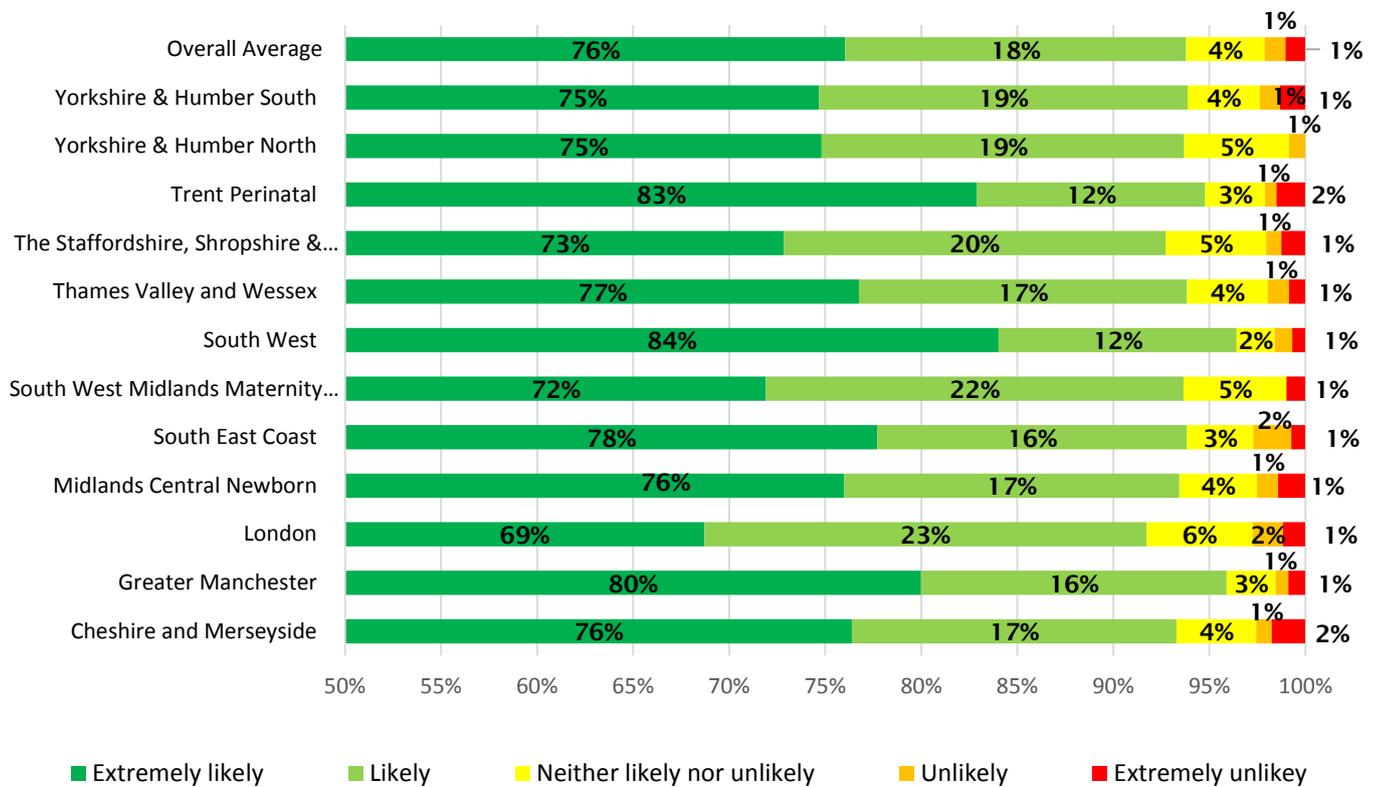
**Graph G4. Did you feel prepared for your baby's discharge from neonatal care? (Overall n=5903)**



**Graph G5. Were you given enough information on what to expect in terms of your baby's progress and recovery? (Overall n=5903)**



**Graph G6. How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment? (Overall n=5153)**



Section Five

## Overall Results by Unit Type

*Overview by section*



## Overall Results by Unit Type

This section shows the overall results for all participating neonatal units by unit type (special care baby units; local neonatal units; neonatal intensive care units) and a comparison against the overall average for all participating units. The results are presented in graphical format only by the sections in the questionnaire. Table 6 below presents units included in the breakdowns by unit type.

Table 6. List of neonatal units per unit type

| Unit Type                     | Unit Name                                     |
|-------------------------------|---|
| <b>Special Care Baby Unit</b> | YEOVIL DISTRICT HOSPITAL                      |
|                               | THE ROYAL FREE HOSPITAL                       |
|                               | EALING HOSPITAL                               |
|                               | SCARBOROUGH HOSPITAL                          |
|                               | KING GEORGE HOSPITAL                          |
|                               | QUEEN ELIZABETH HOSPITAL WOOLWICH             |
|                               | QUEEN'S HOSPITAL, BURTON UPON TRENT           |
|                               | GEORGE ELIOT HOSPITAL                         |
|                               | BASSETLAW DISTRICT GENERAL HOSPITAL           |
|                               | GOOD HOPE HOSPITAL                            |
|                               | HORTON GENERAL HOSPITAL                       |
|                               | THE QUEEN ELIZABETH THE QUEEN MOTHER HOSPITAL |
|                               | ALEXANDRA HOSPITAL                            |
|                               | CONQUEST HOSPITAL                             |
|                               | DEWSBURY AND DISTRICT HOSPITAL                |

Table 6. *continued*

| Unit Type                  | Unit Name  |
|----------------------------|--|
| <b>Local Neonatal Unit</b> | ST MARY'S HOSPITAL, ISLE OF WIGHT                            |
|                            | WHIPPS CROSS UNIVERSITY HOSPITAL AND NEWHAM GENERAL HOSPITAL |
|                            | KINGSTON HOSPITAL  |
|                            | MUSGROVE PARK HOSPITAL                                       |
|                            | WHISTON HOSPITAL   |
|                            | ALDER HEY HOSPITAL   |
|                            | YORK HOSPITAL  |
|                            | SHEFFIELD CHILDREN'S HOSPITAL NEONATAL SURGICAL UNIT         |
|                            | WEXHAM PARK HOSPITAL   |
|                            | MILTON KEYNES HOSPITAL                                       |
|                            | FRIMLEY PARK HOSPITAL  |
|                            | ROYAL CORNWALL HOSPITAL                                      |
|                            | ROTHERHAM DISTRICT GENERAL HOSPITAL                          |
|                            | CHESTERFIELD ROYAL HOSPITAL                                  |
|                            | ROYAL DEVON AND EXETER HOSPITAL                              |
|                            | UNIVERSITY HOSPITAL LEWISHAM                                 |
|                            | DIANA PRINCESS OF WALES HOSPITAL                             |
|                            | SCUNTHORPE GENERAL HOSPITAL                                  |
|                            | MACCLESFIELD DISTRICT GENERAL HOSPITAL                       |
|                            | COUNTESS OF CHESTER HOSPITAL                                 |
|                            | KING'S MILL HOSPITAL   |
|                            | WYTHENSHAW HOSPITAL  |
|                            | THE GREAT WESTERN HOSPITAL                                   |
|                            | RUSSELLS HALL HOSPITAL                                       |
|                            | NORTHAMPTON GENERAL HOSPITAL                                 |
|                            | SALISBURY DISTRICT HOSPITAL                                  |
|                            | DONCASTER ROYAL INFIRMARY                                    |
|                            | ROYAL ALBERT EDWARD INFIRMARY                                |
|                            | GLOUCESTERSHIRE ROYAL HOSPITAL                               |
|                            | EAST SURREY HOSPITAL   |
|                            | NORTHWICK PARK HOSPITAL                                      |
|                            | ORMSKIRK & DISTRICT GENERAL HOSPITAL                         |
|                            | NORTH MANCHESTER GENERAL HOSPITAL                            |
|                            | ROYAL OLDHAM HOSPITAL  |
|                            | WORCESTERSHIRE ROYAL HOSPITAL                                |
|                            | WARRINGTON HOSPITAL  |
|                            | CALDERDALE ROYAL HOSPITAL                                    |
|                            | PINDERFIELDS GENERAL HOSPITAL                                |
|                            | STOKE MANDEVILLE HOSPITAL                                    |
|                            | PRINCESS ROYAL HOSPITAL                                      |
| ST MARY'S HOSPITAL         |  |

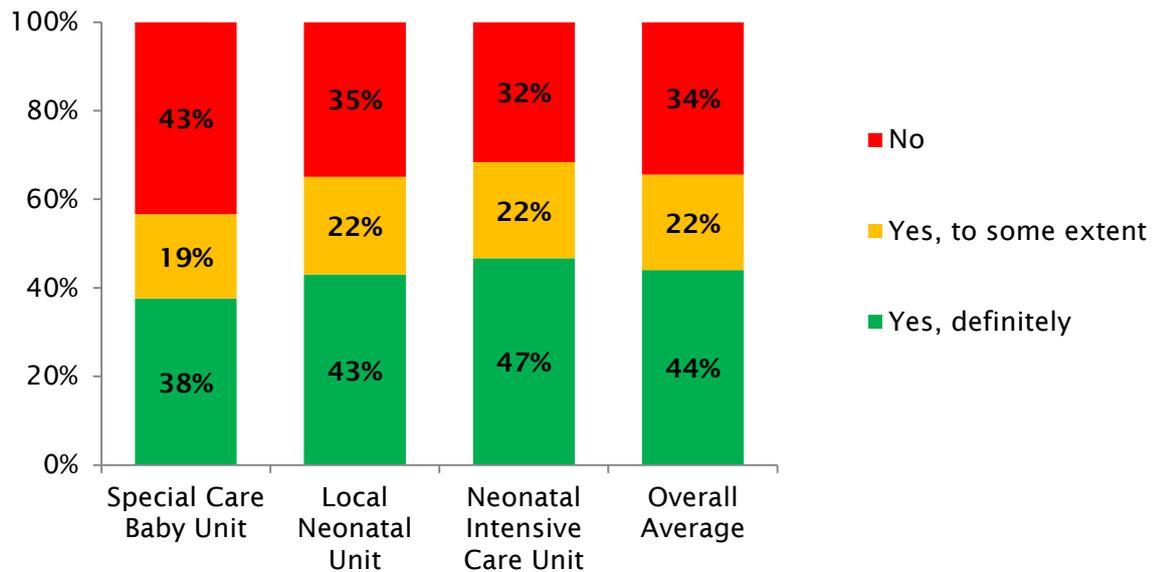
Table 6. *continued*

| Unit Type                              | Unit Name                                  |
|--|--|
| <b>Neonatal Intensive Care Unit</b>    | THE ROYAL LONDON HOSPITAL                  |
|  | ST MICHAEL'S HOSPITAL                      |
|  | BRADFORD ROYAL INFIRMARY MATERNITY UNIT    |
|  | ARROWE PARK HOSPITAL                       |
|  | LIVERPOOL WOMENS HOSPITAL                  |
|  | QUEEN'S HOSPITAL, ROMFORD                  |
|  | NOTTINGHAM CITY HOSPITAL                   |
|  | PRINCESS ANNE HOSPITAL                     |
|  | THE JESSOP WING, SHEFFIELD                 |
|  | QUEEN ALEXANDRA HOSPITAL                   |
|  | ST THOMAS' HOSPITAL                        |
|  | ST GEORGE'S HOSPITAL                       |
|  | UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE |
|  | DERRIFORD HOSPITAL                         |
|  | UNIVERSITY HOSPITAL COVENTRY               |
|  | BIRMINGHAM WOMEN'S HOSPITAL                |
|  | ROYAL BOLTON HOSPITAL                      |
|  | MEDWAY MARITIME HOSPITAL                   |
|  | CHELSEA & WESTMINSTER HOSPITAL             |
|  | BIRMINGHAM HEARTLANDS HOSPITAL             |
|  | LEEDS NEONATAL SERVICE                     |
|  | UNIVERSITY COLLEGE HOSPITAL                |
|  | QUEENS MEDICAL CENTRE                      |
|  | JOHN RADCLIFFE HOSPITAL                    |
|  | ST PETER'S HOSPITAL                        |
|  | SOUTHMEAD HOSPITAL                         |
|  | WILLIAM HARVEY HOSPITAL                    |
|  | ST MARY'S HOSPITAL, MANCHESTER             |
| LEICESTER NEONATAL SERVICE             |  |
| ROYAL PRESTON HOSPITAL                 |  |
| QUEEN CHARLOTTE'S AND CHELSEA HOSPITAL |  |

Figure 11: Graphs by unit type:

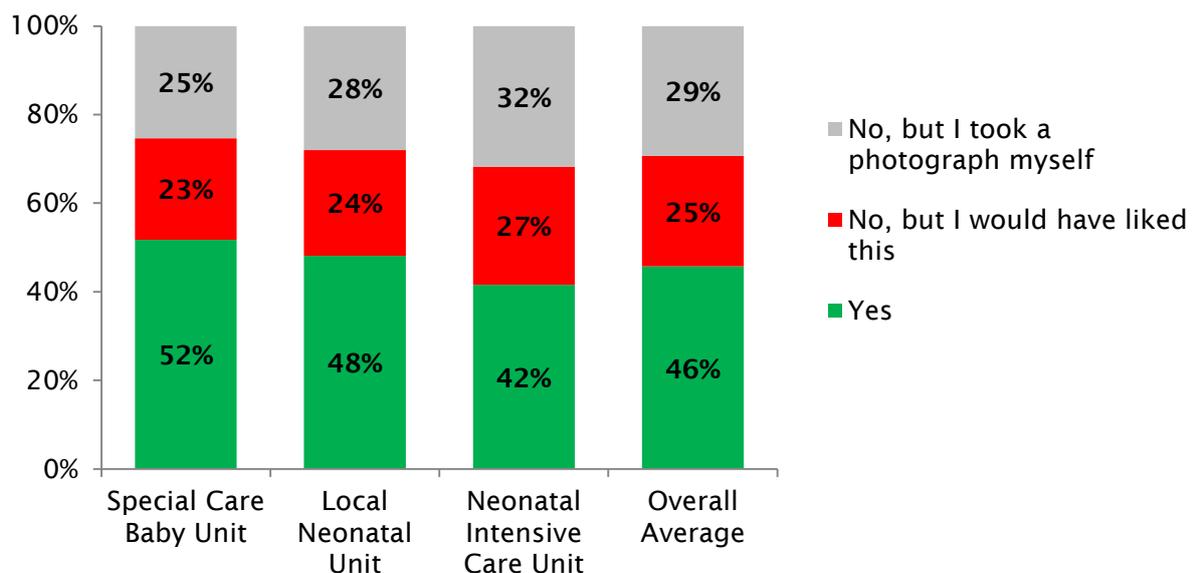
### A. Before your baby was born

A2. Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth? (Overall n=1919)

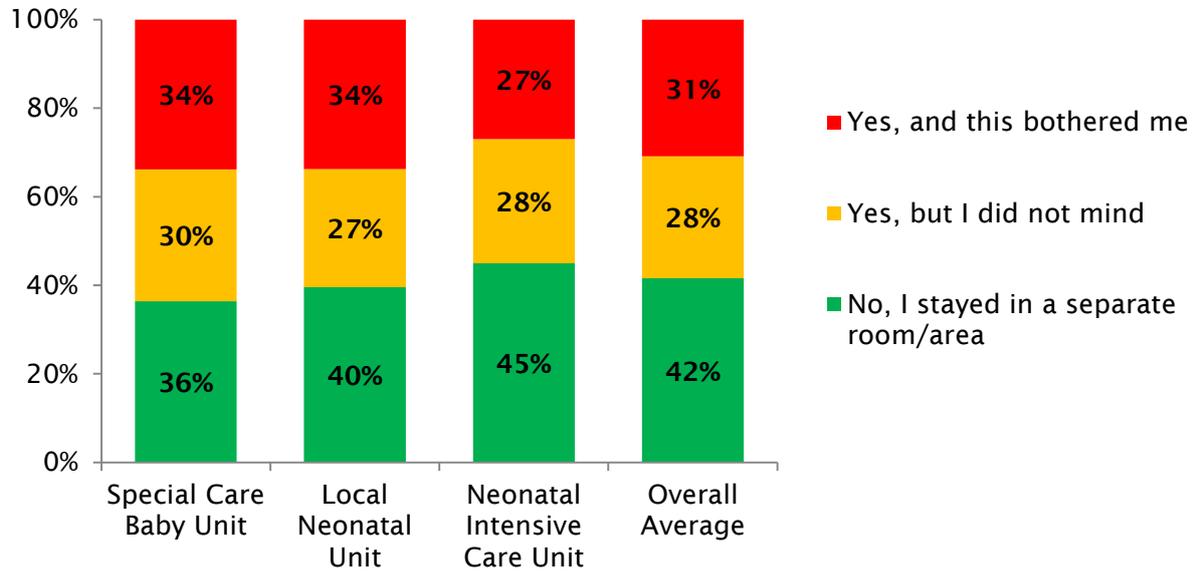


### B. Your baby's admission to neonatal care

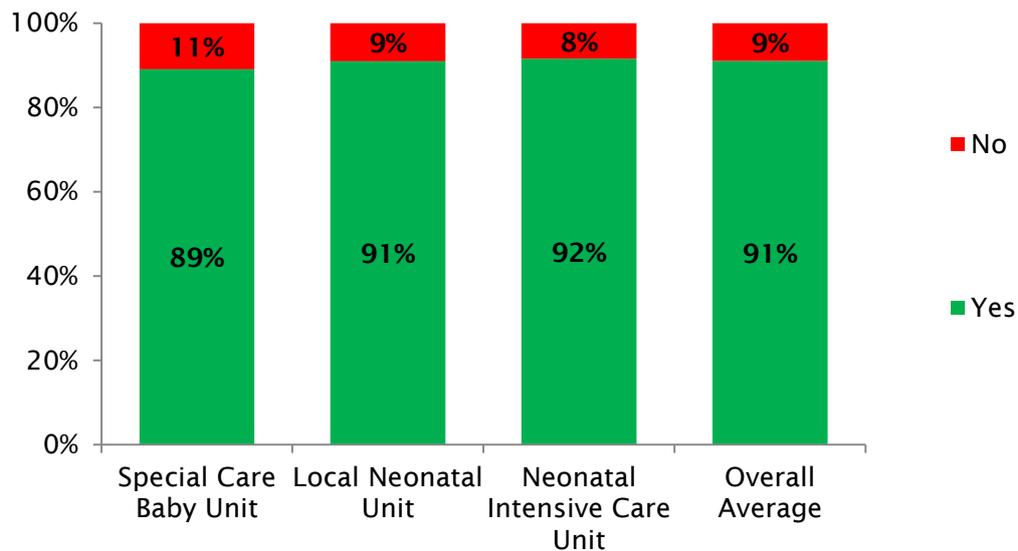
B2. After you gave birth, were you offered a photograph of your baby? (Overall n=4972)



**B3. After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them? (Overall n=5167)**

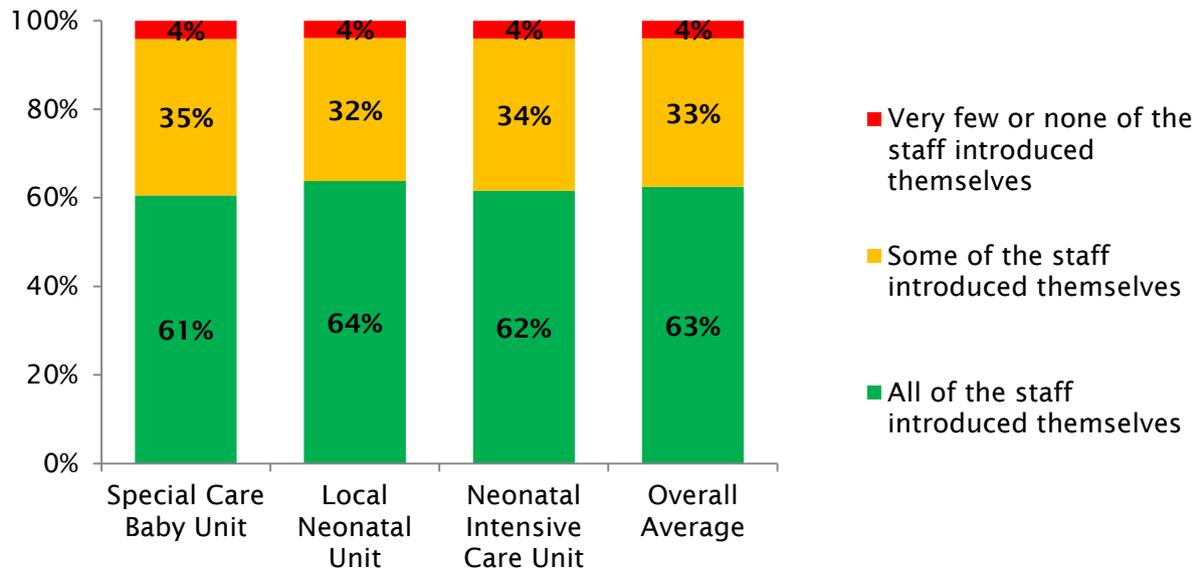


**B4. After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted? (Overall n=3858)**

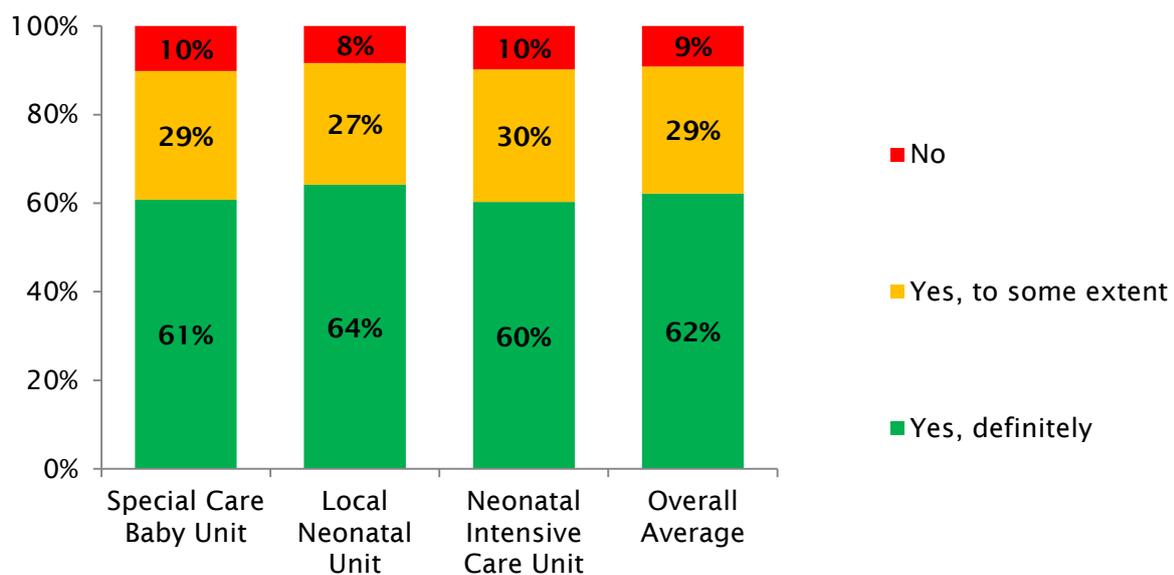


### C. Staff on the neonatal unit

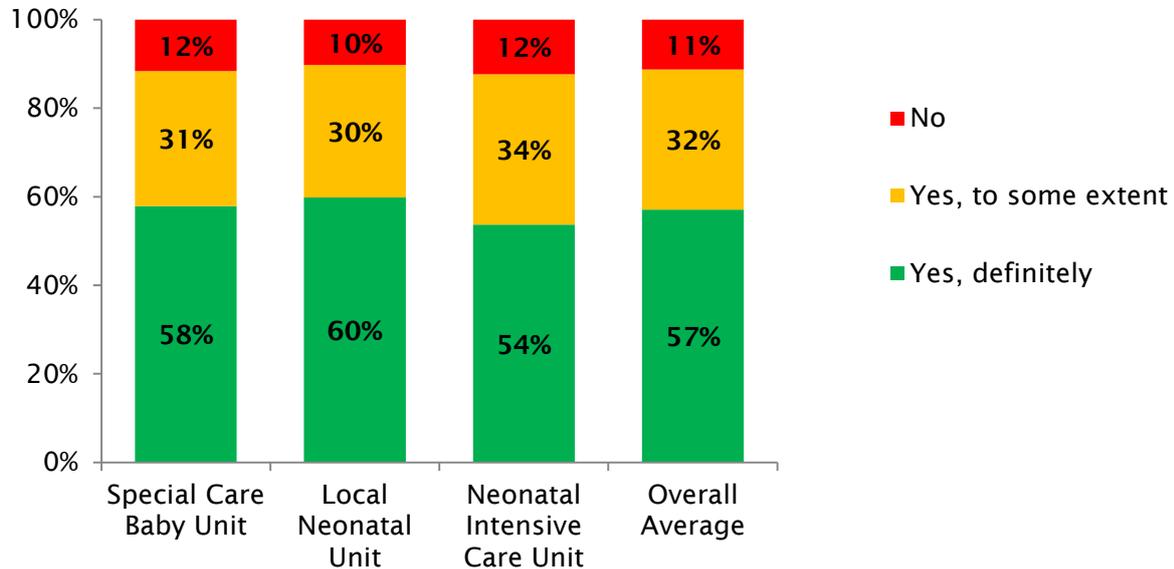
C1. When you visited the unit, did the staff caring for your baby introduce themselves to you? (Overall n=5804)



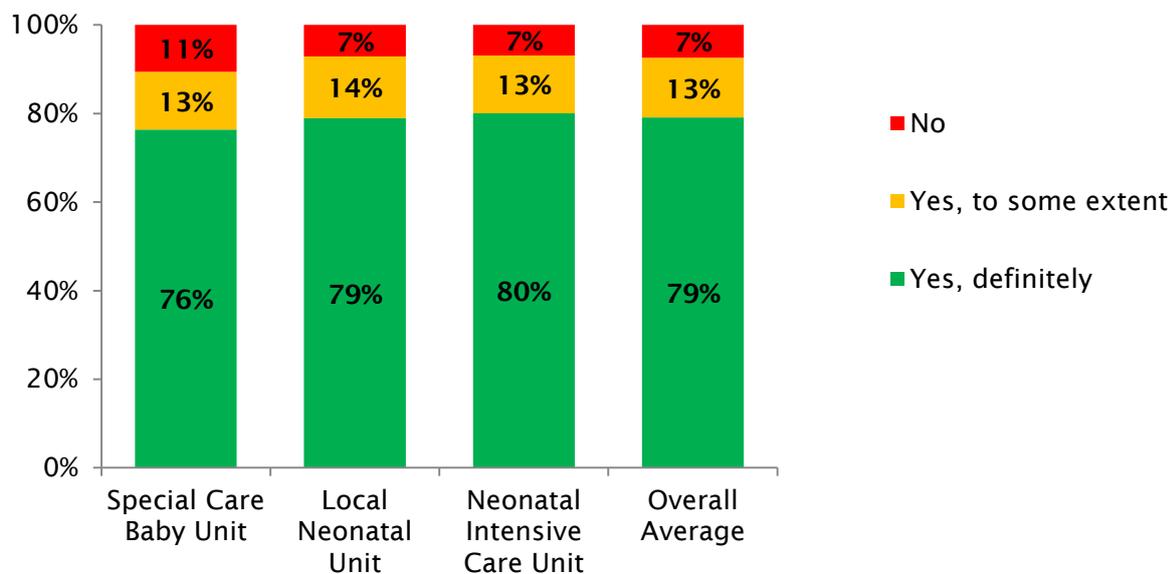
C2. Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)? (Overall n=5804)



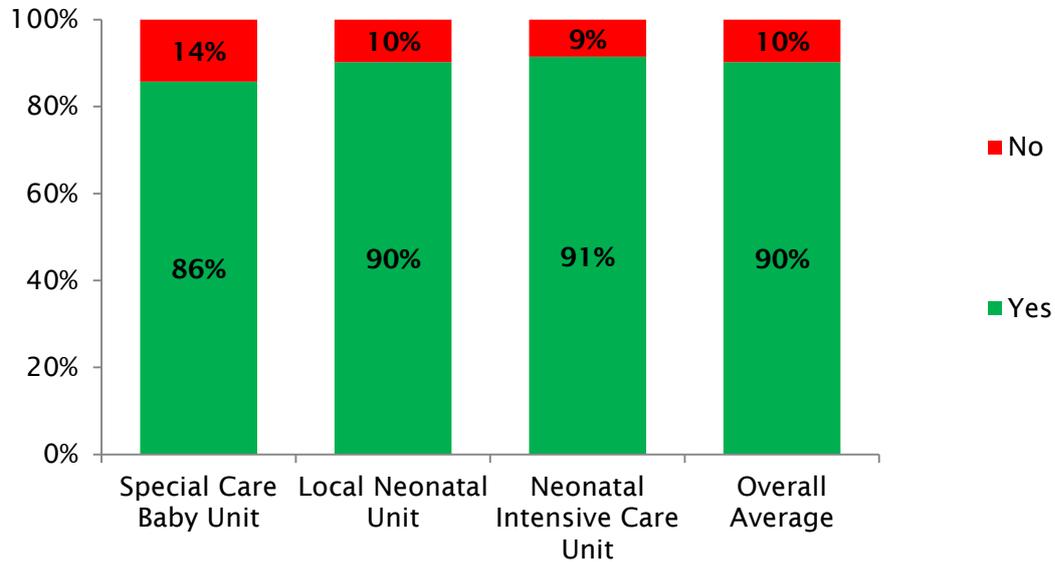
**C3. Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you? (Overall n=5767)**



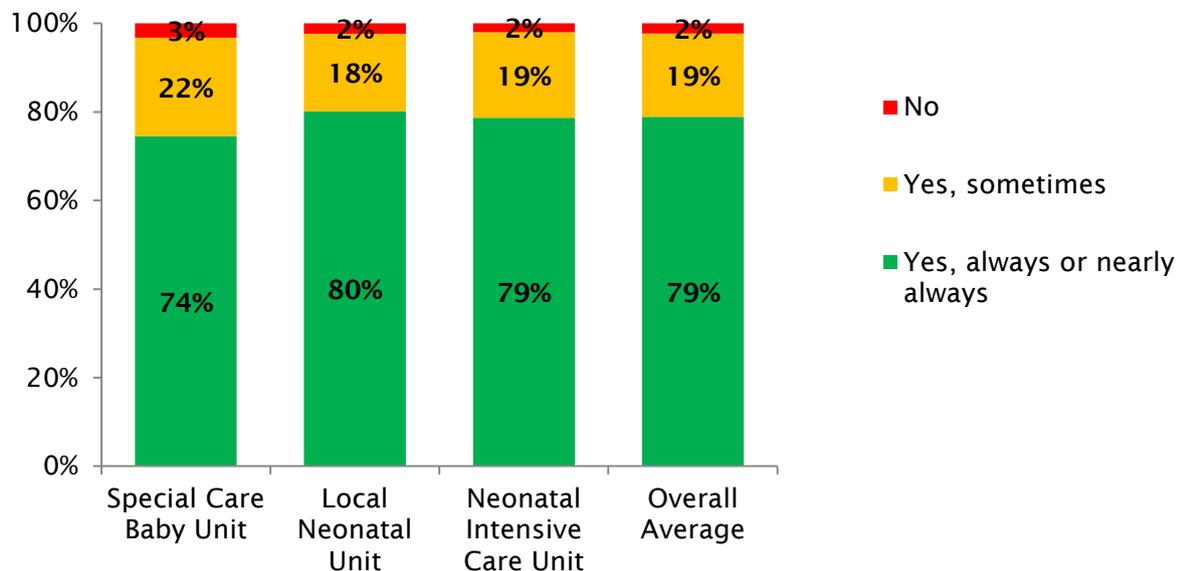
**C4. Were infection control practices explained to you, such as hand washing and procedures for visitors? (Overall n=5820)**



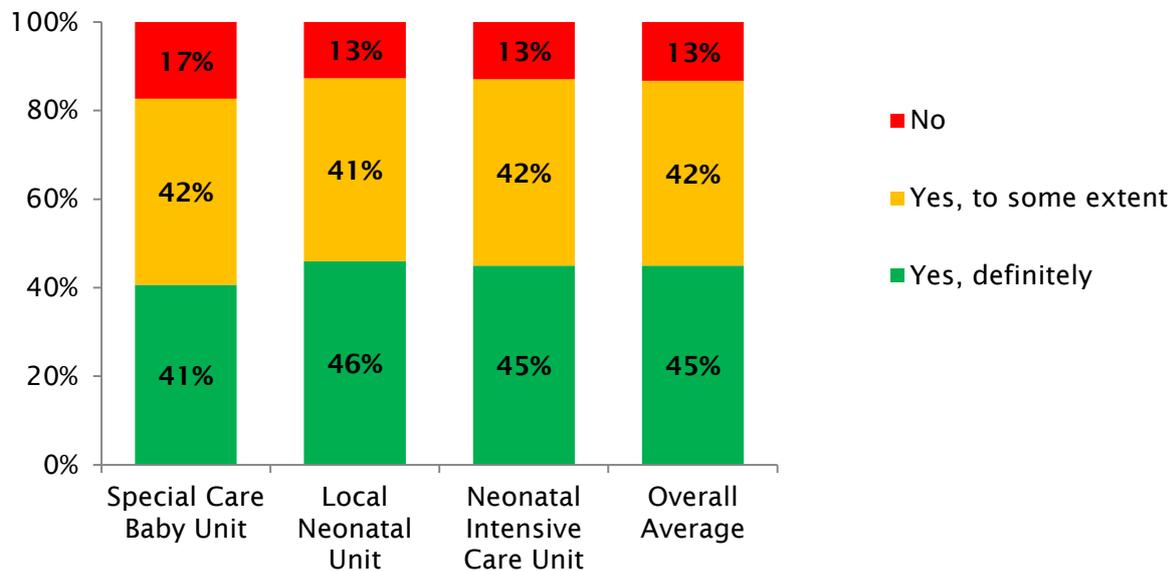
**C5. Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit? (Overall n=5888)**



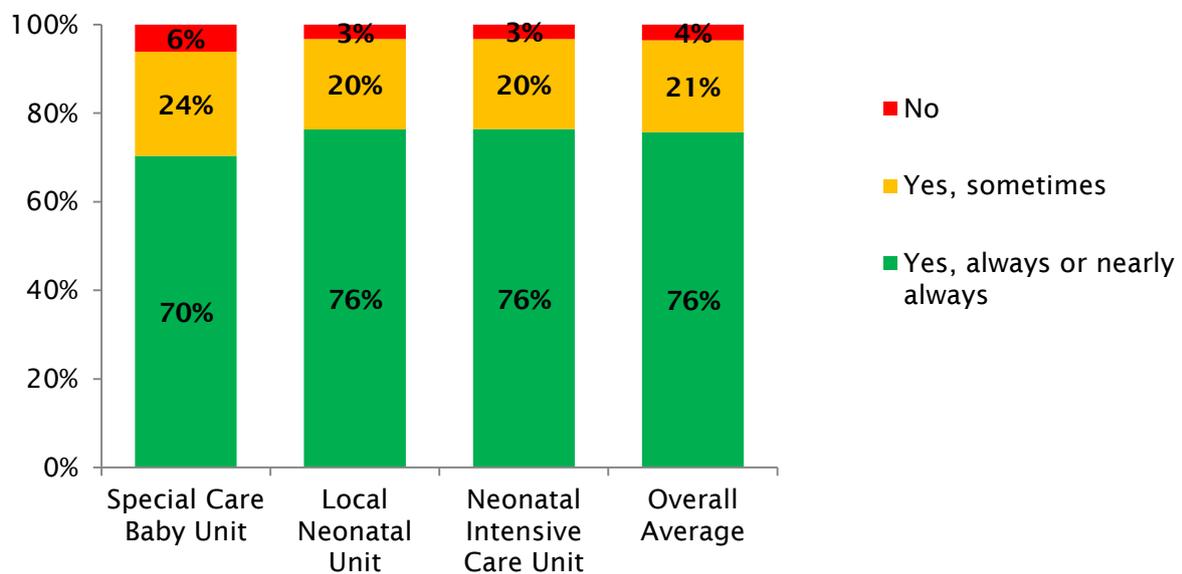
**C6. Were you able to talk to staff on the unit about your worries and concerns? (Overall n=5848)**



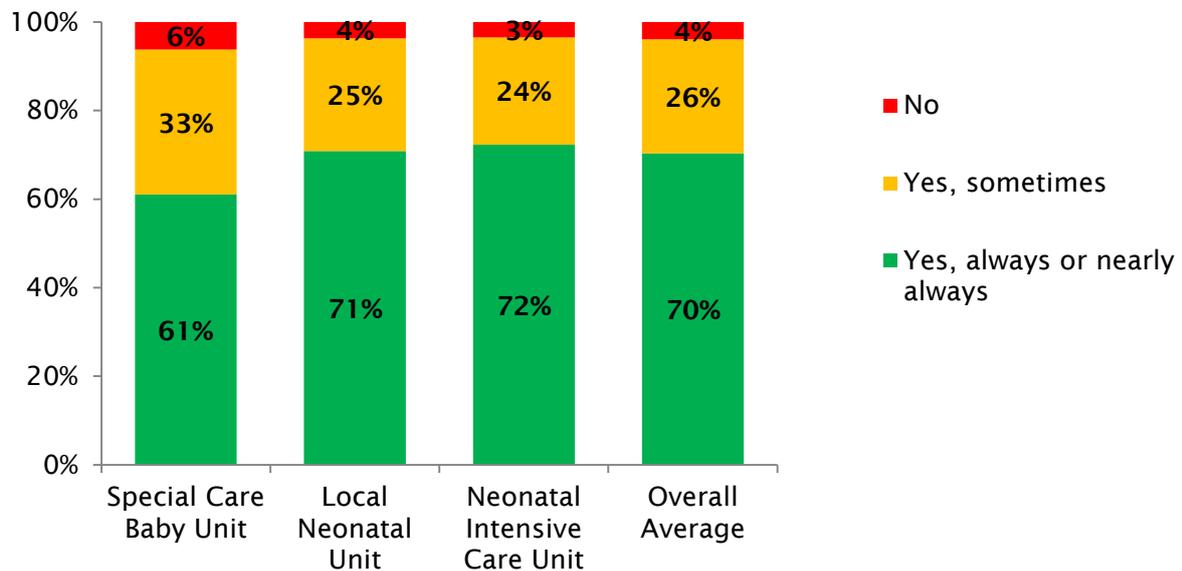
**C7. Were you able to speak to a doctor about your baby as much as you wanted? (Overall n=5687)**



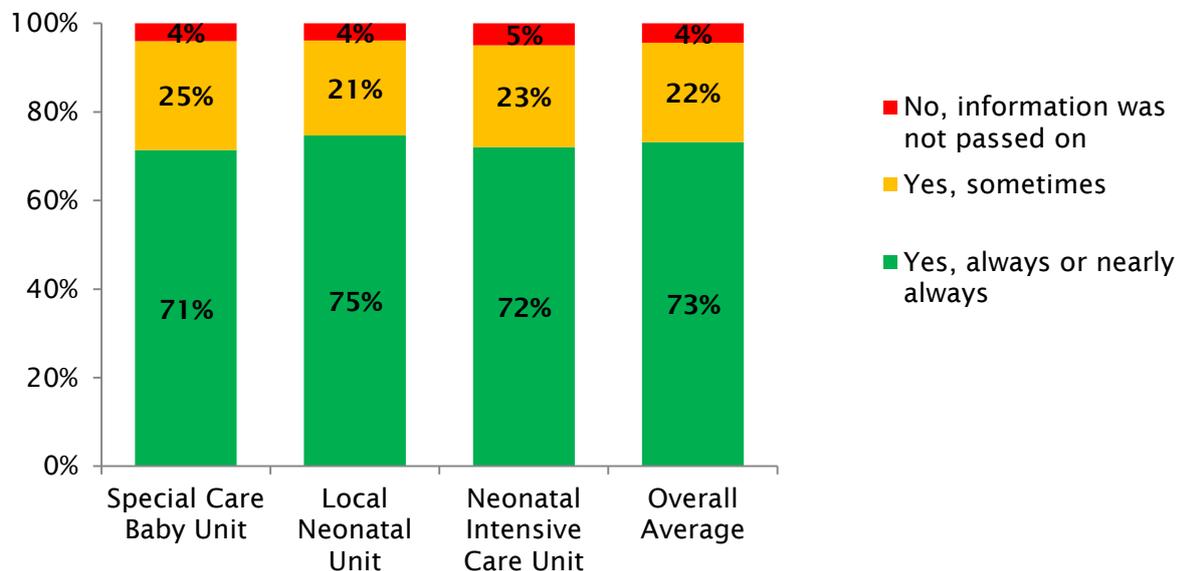
**C8. Were the nurses on the unit sensitive to your emotions and feelings? (Overall n=5786)**



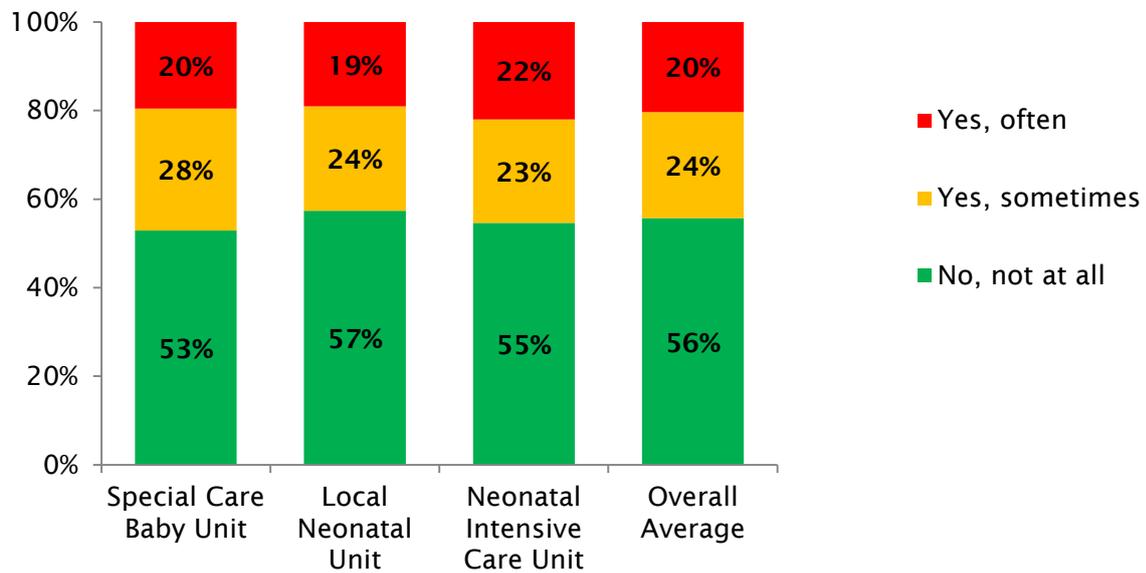
**C9. Were the doctors on the unit sensitive to your emotions and feelings? (Overall n=5365)**



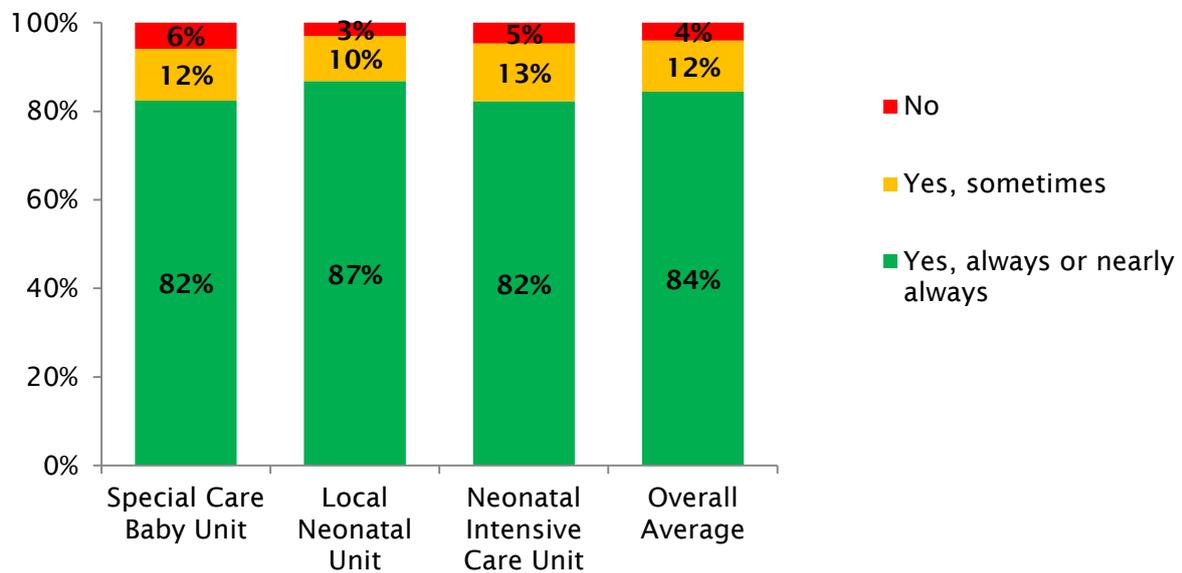
**C10. In your opinion, was important information about your baby passed on from one member of staff to another? (Overall n=5603)**



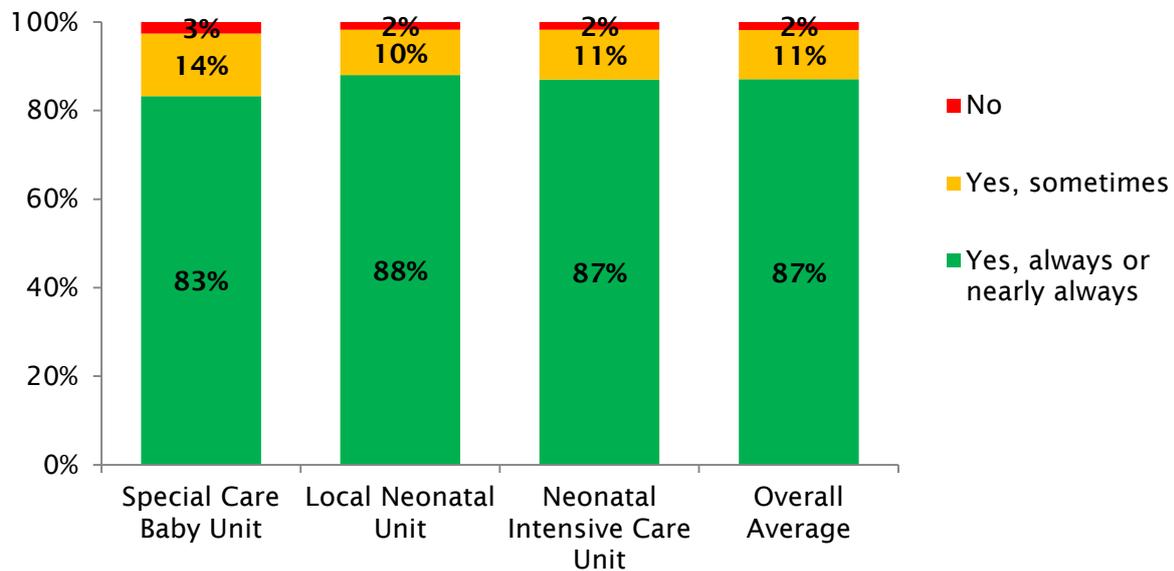
**C11. Did staff give you conflicting information about your baby's condition or care? (Overall n=5868)**



**C12. Did staff refer to your baby by his/her first name? (Overall n=5459)**

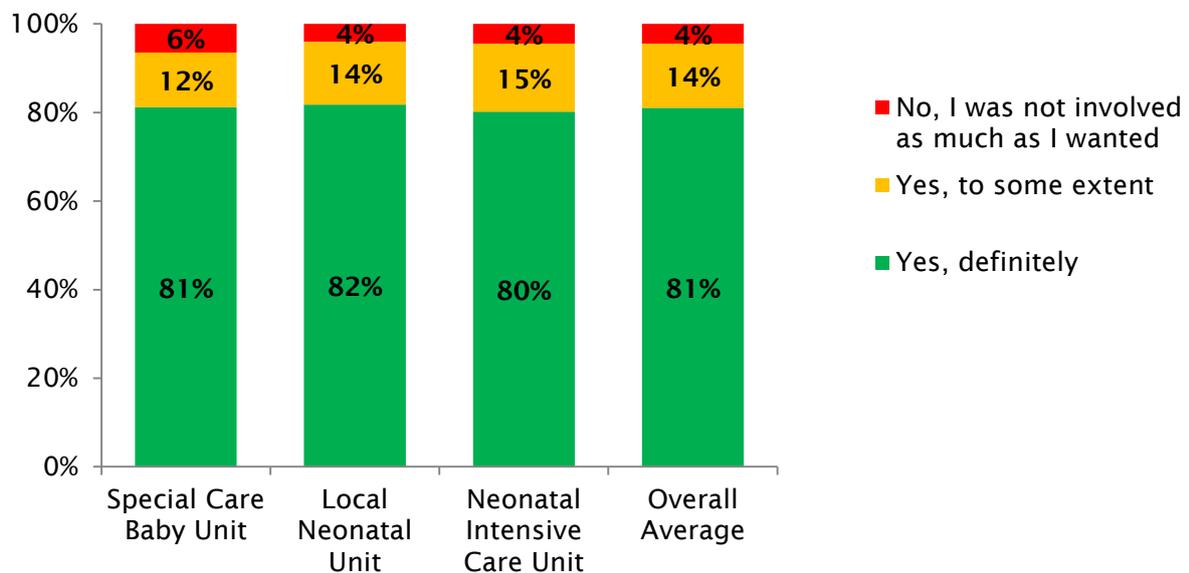


C13. Overall, did you have confidence and trust in the staff caring for your baby? (Overall n=5919)

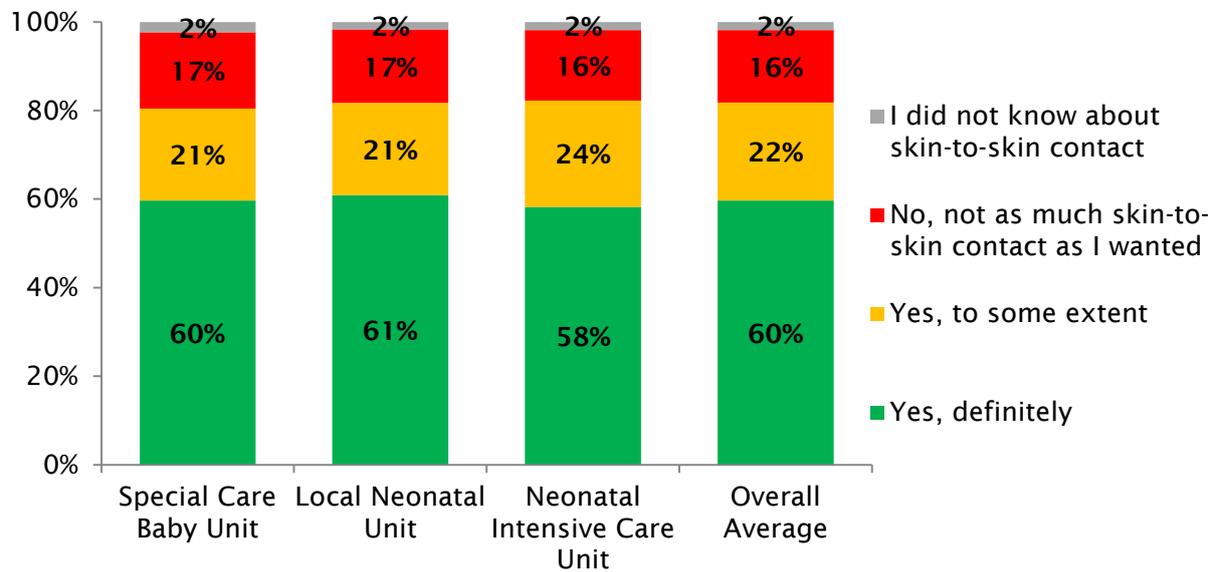


## D. Your involvement in your baby's care

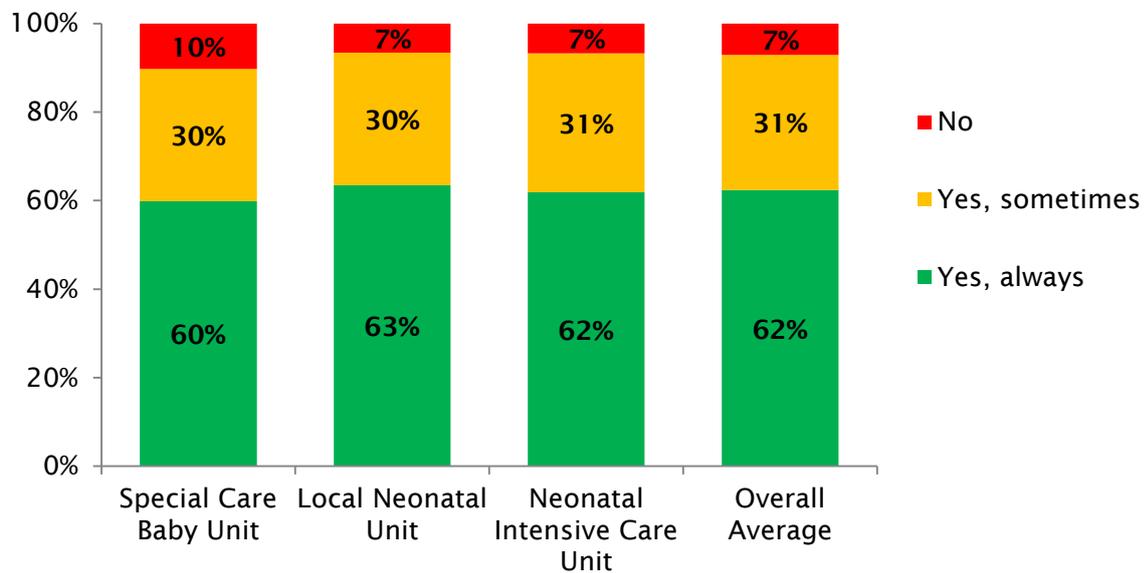
D1. Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding? (Overall n=5852)



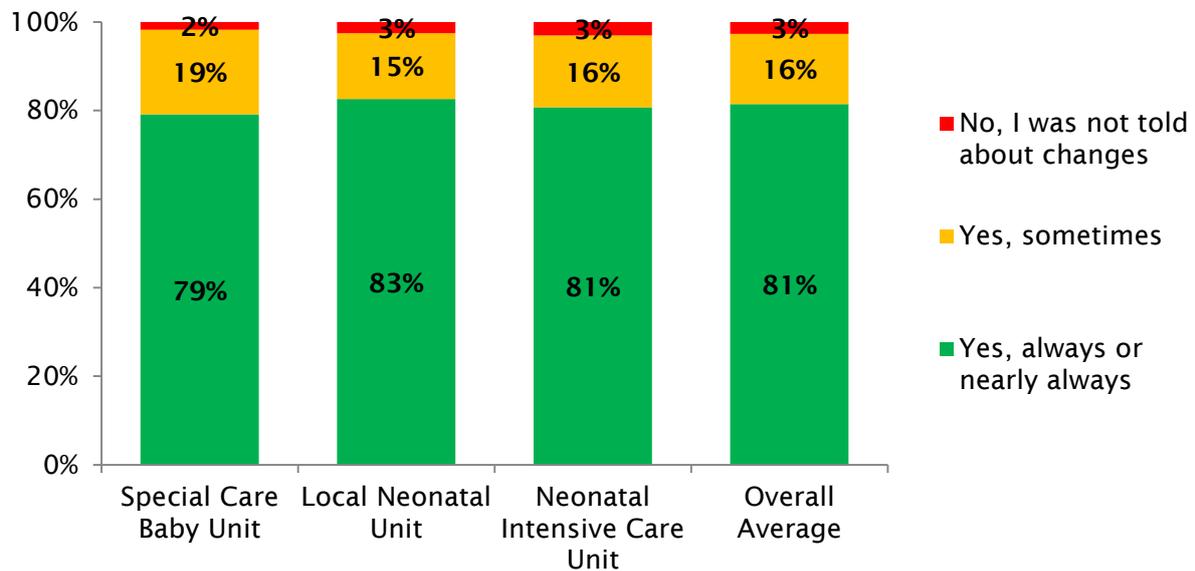
**D2. Did you have as much skin- to-skin contact with your baby as you wanted? (Overall n=5106)**



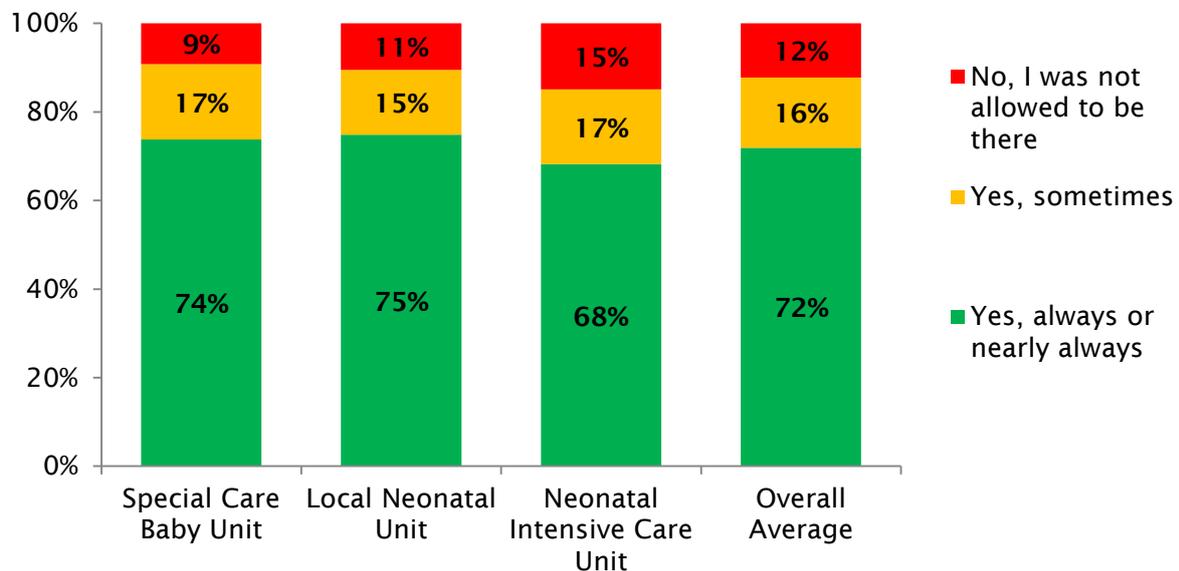
**D3. Did the neonatal staff include you in discussions about your baby's care and treatment? (Overall n=5902)**



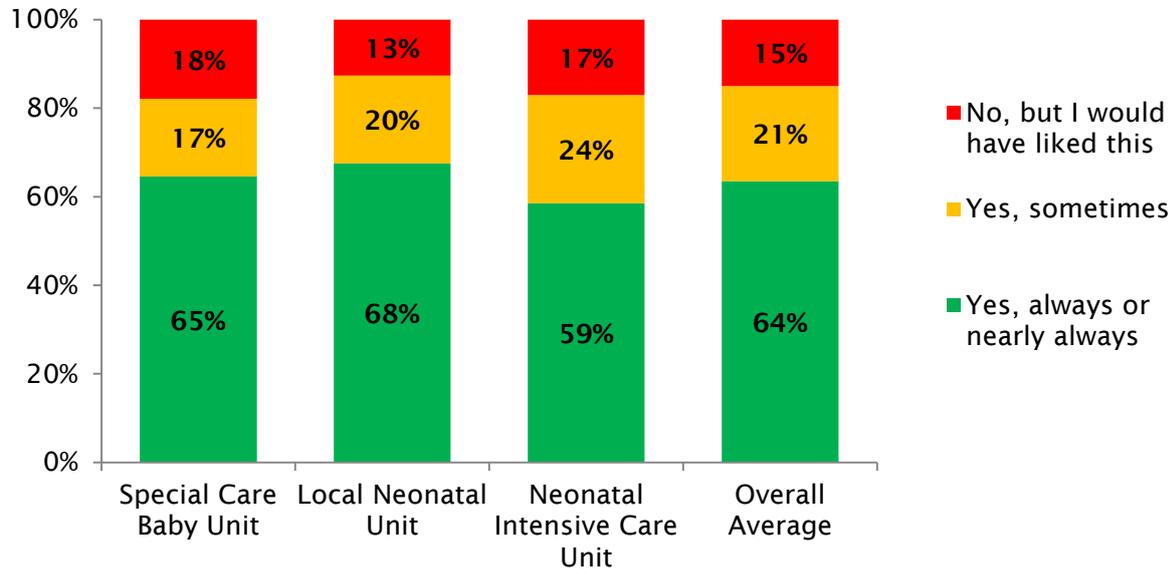
**D4. Were you told about any changes in your baby’s condition or care? (Overall n=5833)**



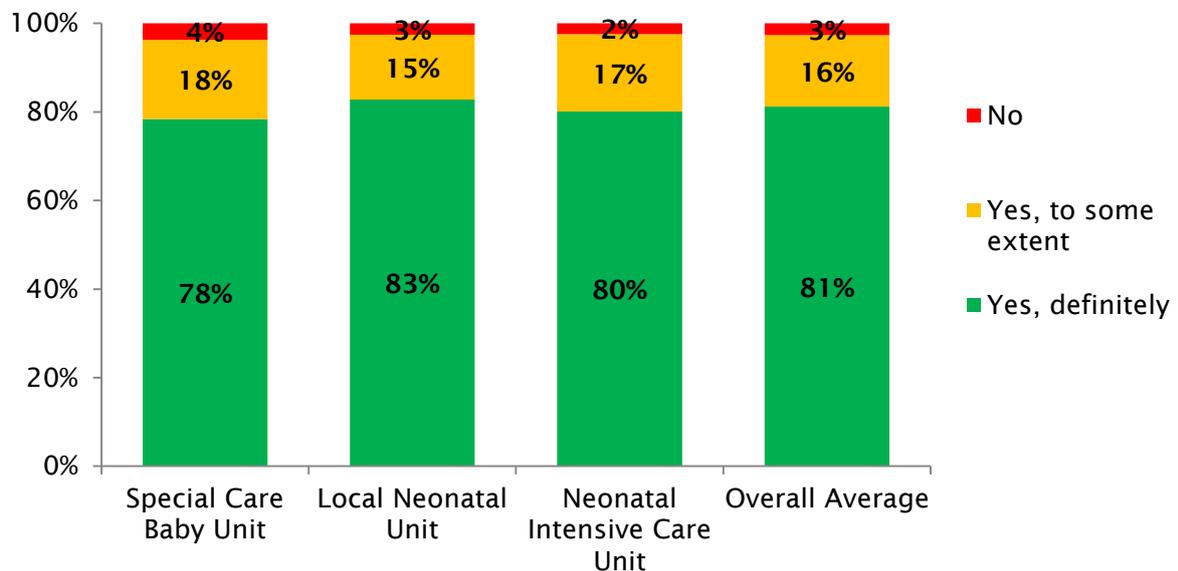
**D5. When a ward round was taking place, were you allowed to be present when your baby was being discussed? (Overall n=5037)**



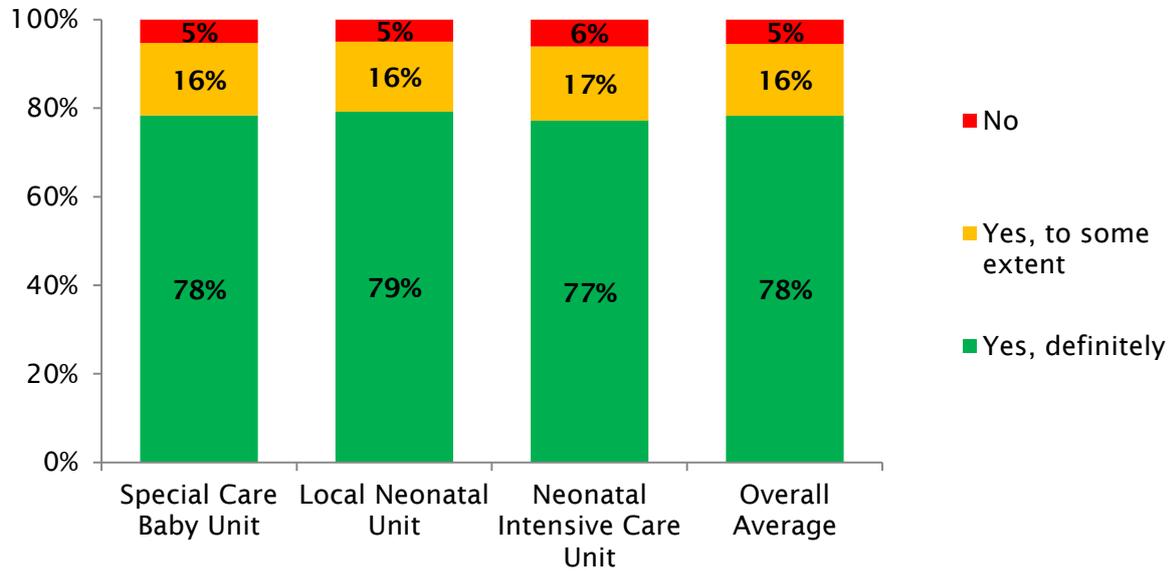
D6. Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times? (Overall n=4615)



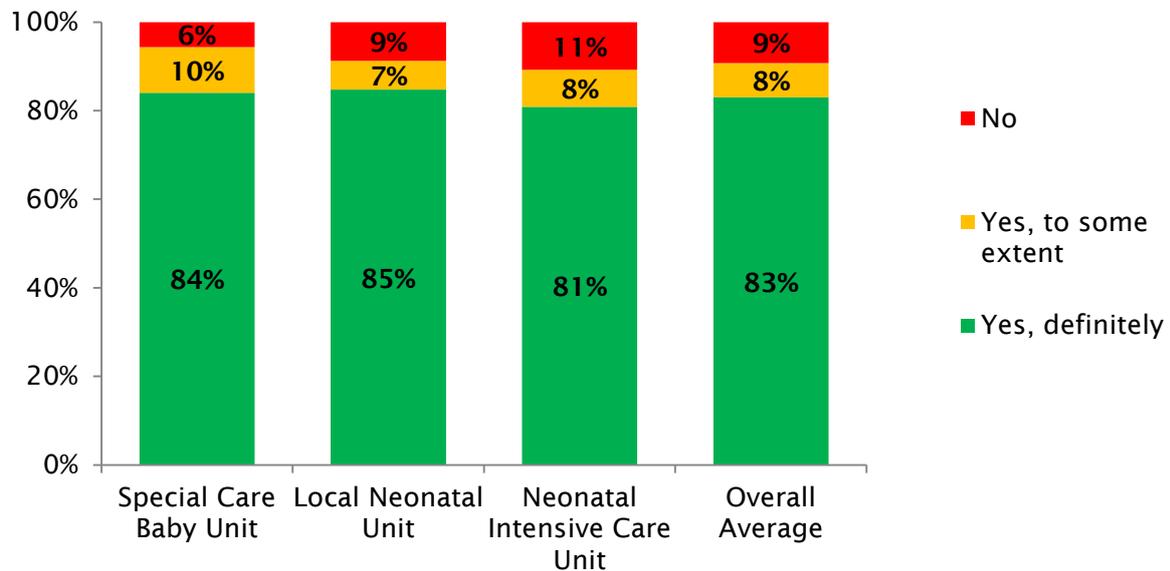
D7. Overall, did staff help you feel confident in caring for your baby? (Overall n=5876)



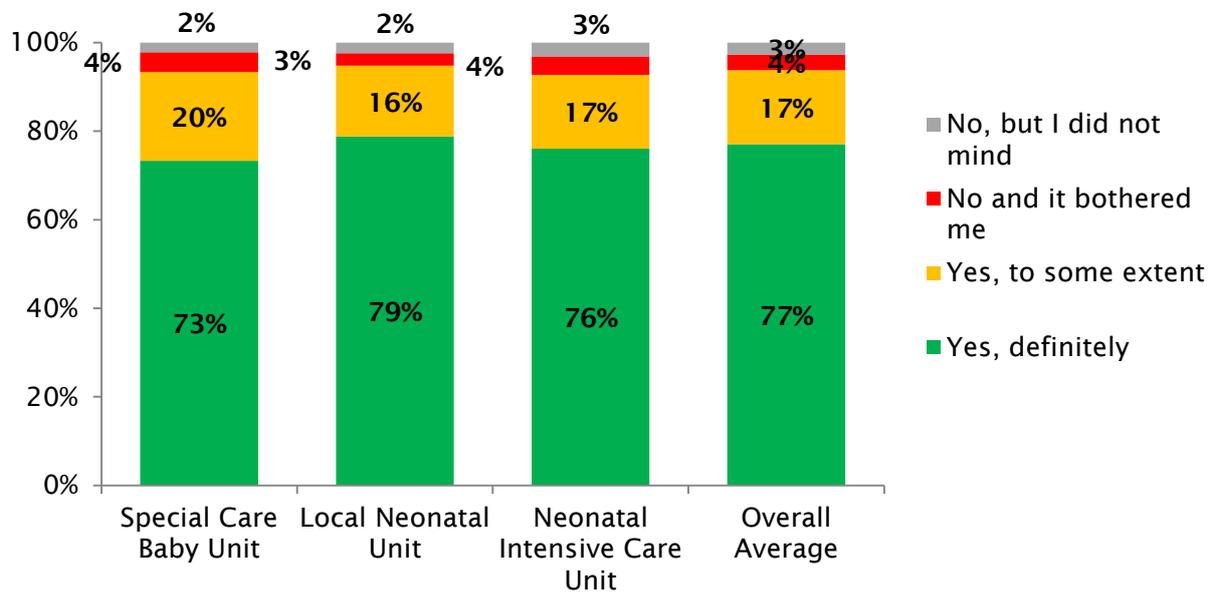
D8. If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff? (Overall n=4735)



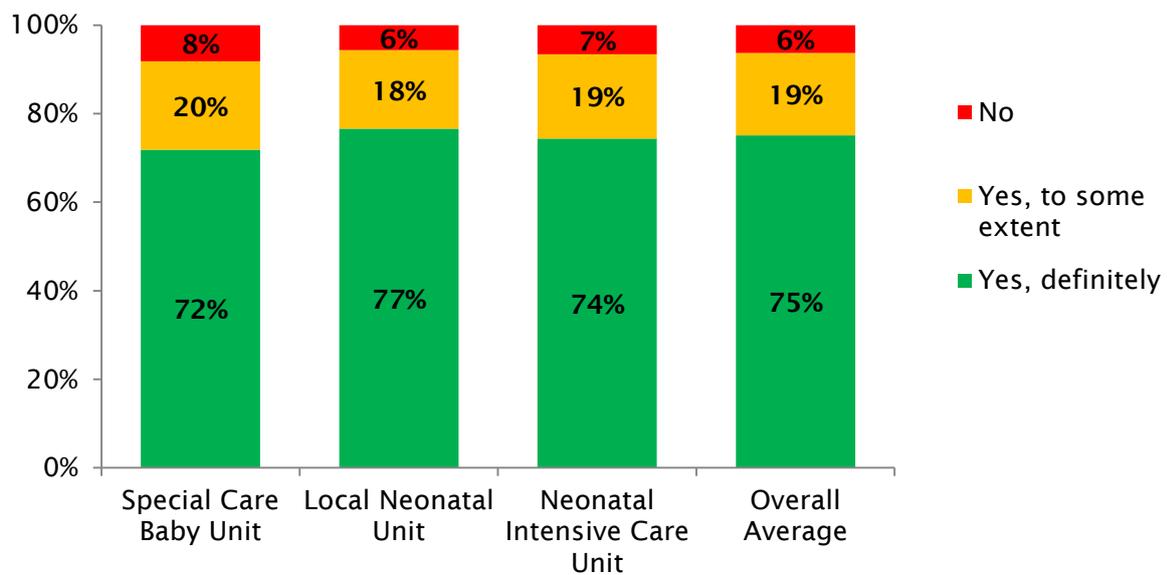
D9. When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as a breast pump and sterilisation equipment? (Overall n=4721)



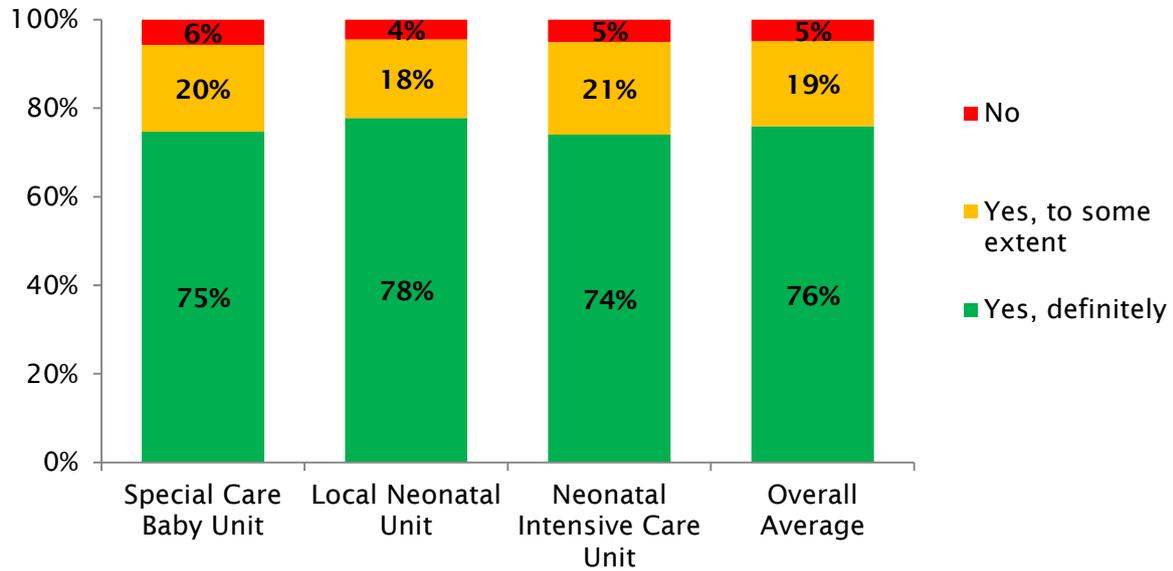
D10. Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby? (Overall n=4682)



D11. If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff? (Overall n=4602)

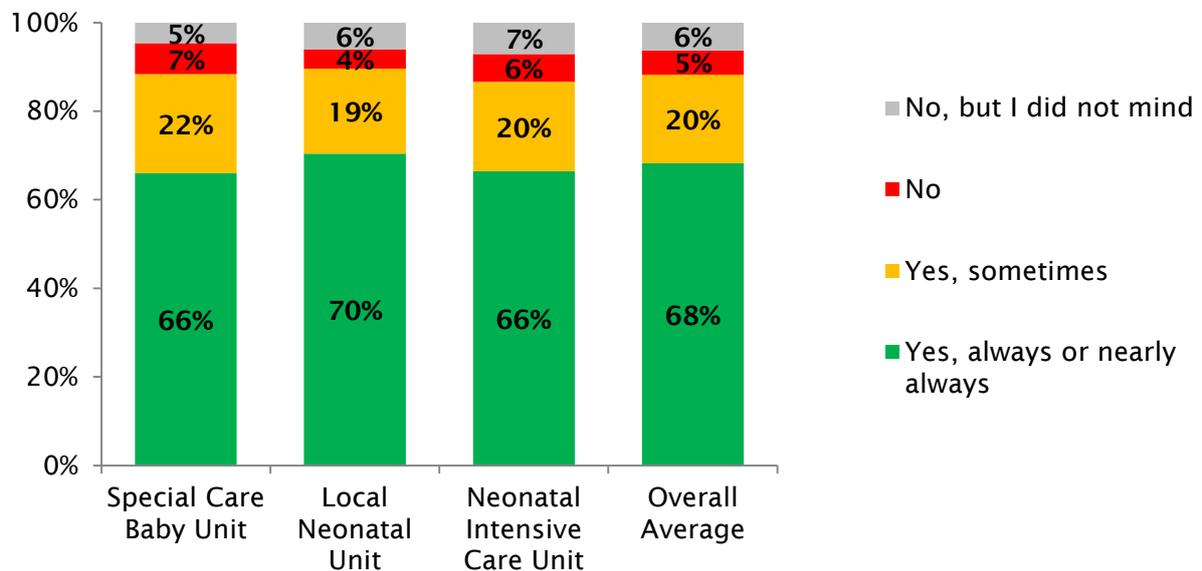


D12. If you fed your baby formula milk, were you given enough support to do this from neonatal staff?  
(Overall n=3507)

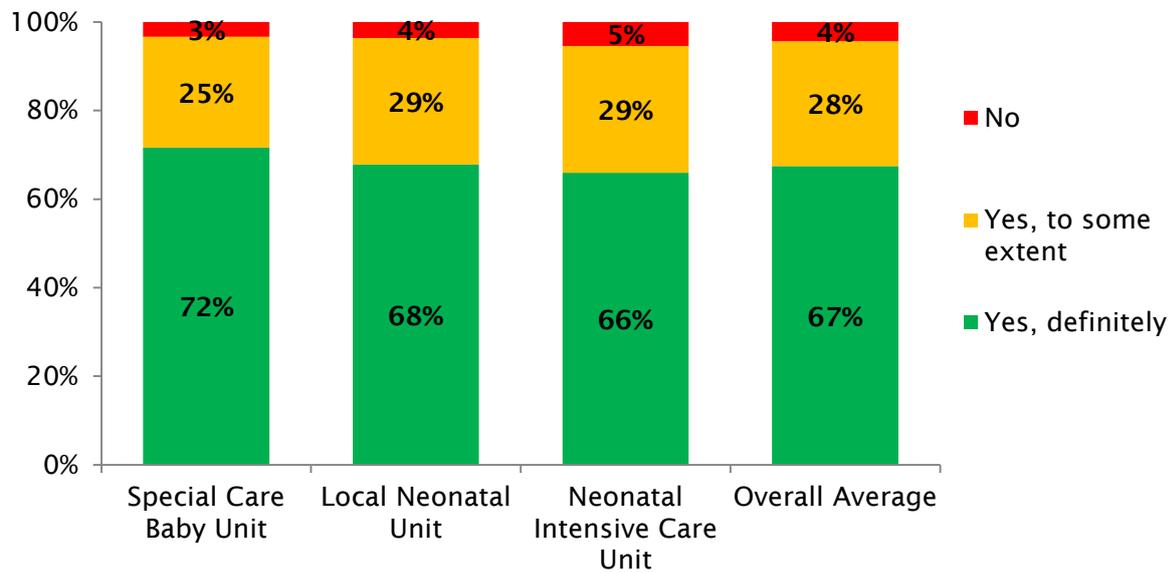


## E. Environment and facilities

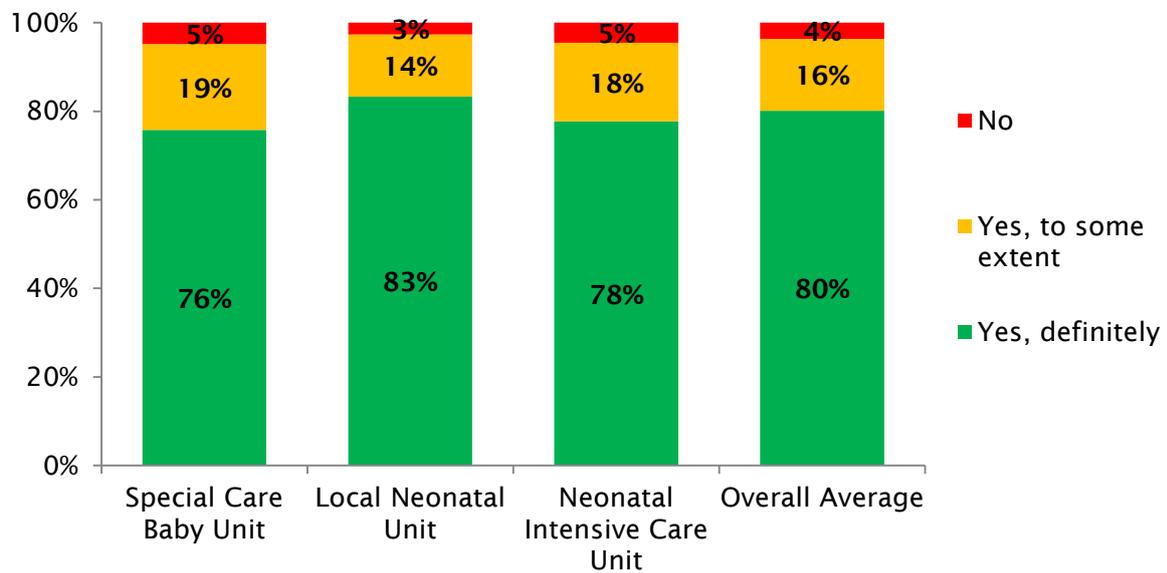
E1. Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?  
(Overall n=5502)



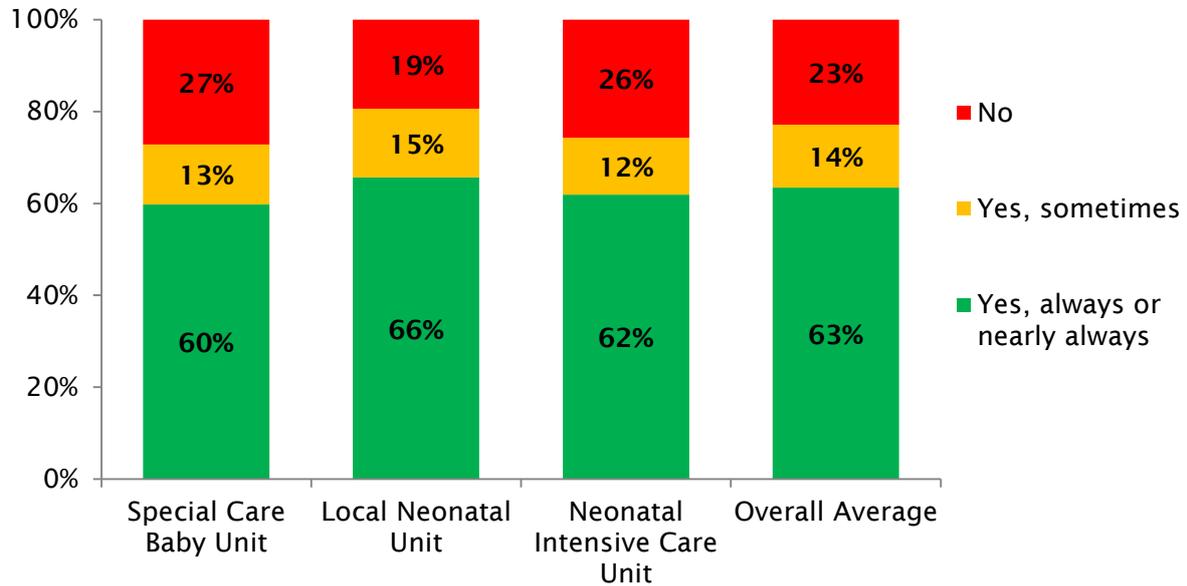
**E2. Was there enough space for you to sit alongside your baby's cot in the unit? (Overall n=5875)**



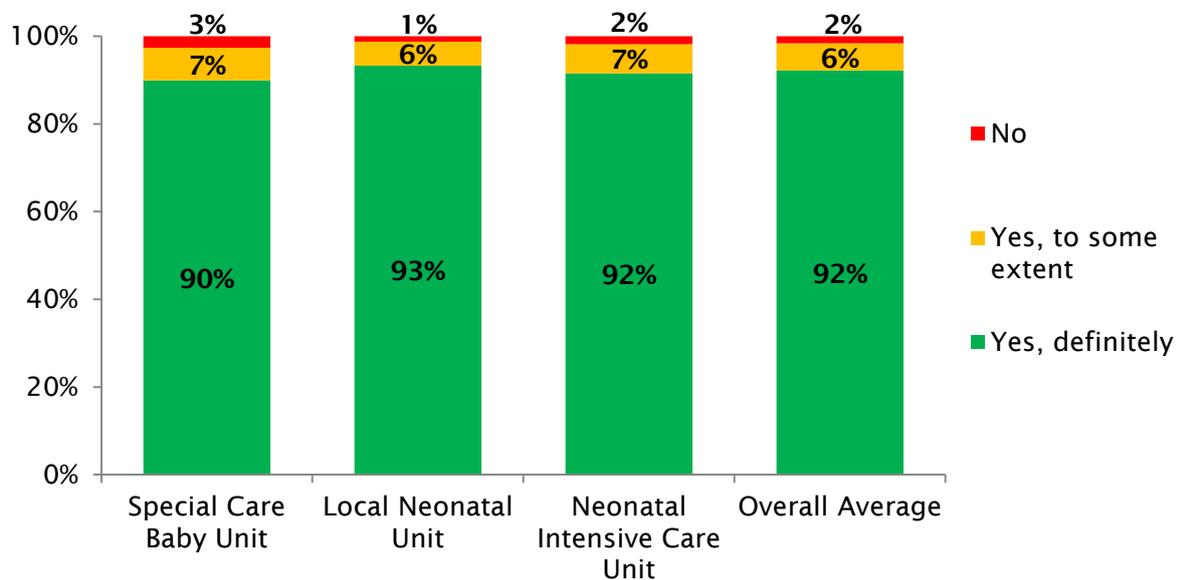
**E3. In your opinion, was there adequate security on the neonatal unit? (Overall n=5894)**



E4. If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation? (Overall n=4538)

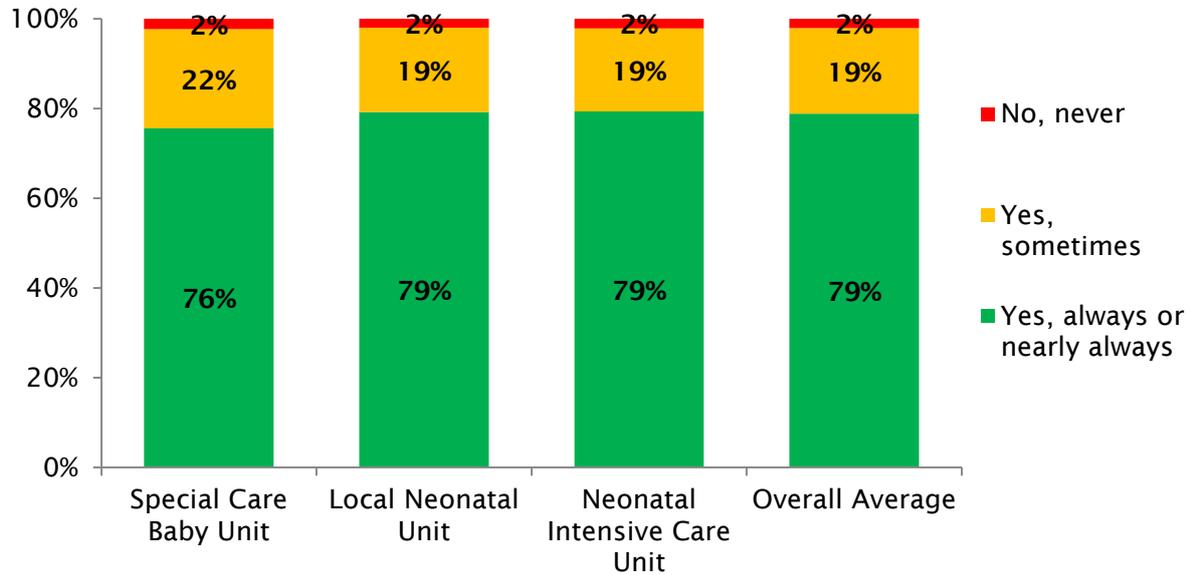


E5. Were you able to visit your baby on the unit as much as you wanted to? (Overall n=5840)

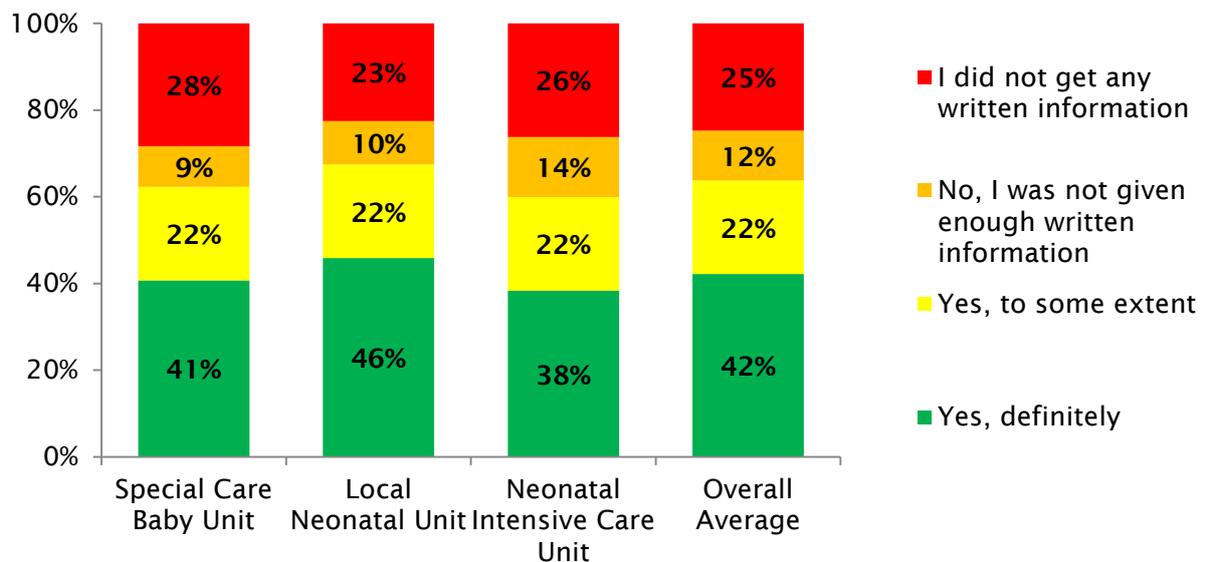


## F. Information and support for parents

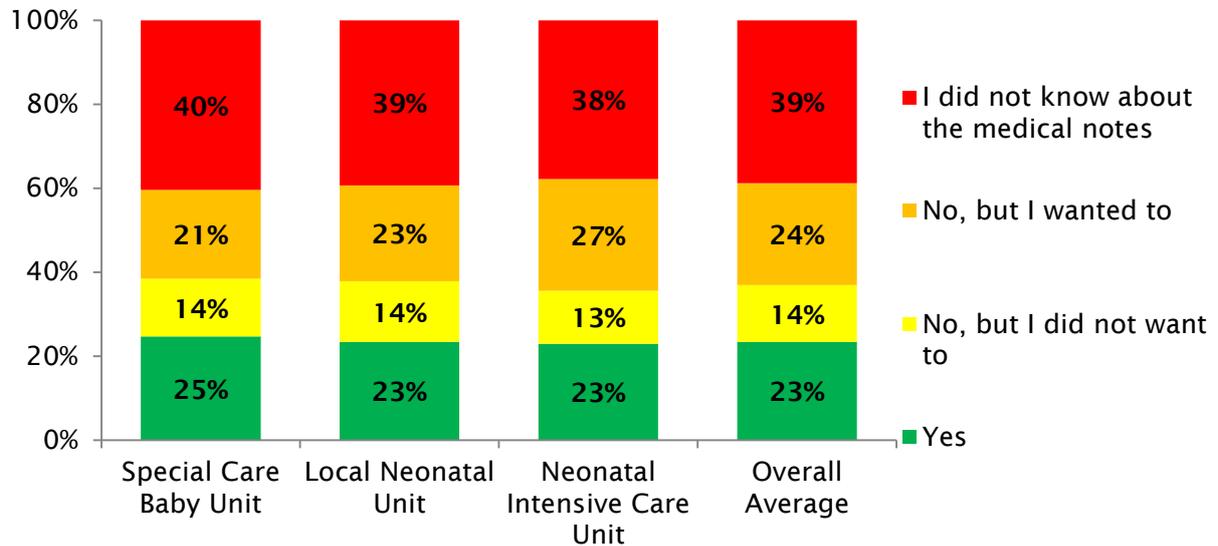
F1. If you asked questions about your baby's condition and treatment, did you get answers you could understand? (Overall n=5898)



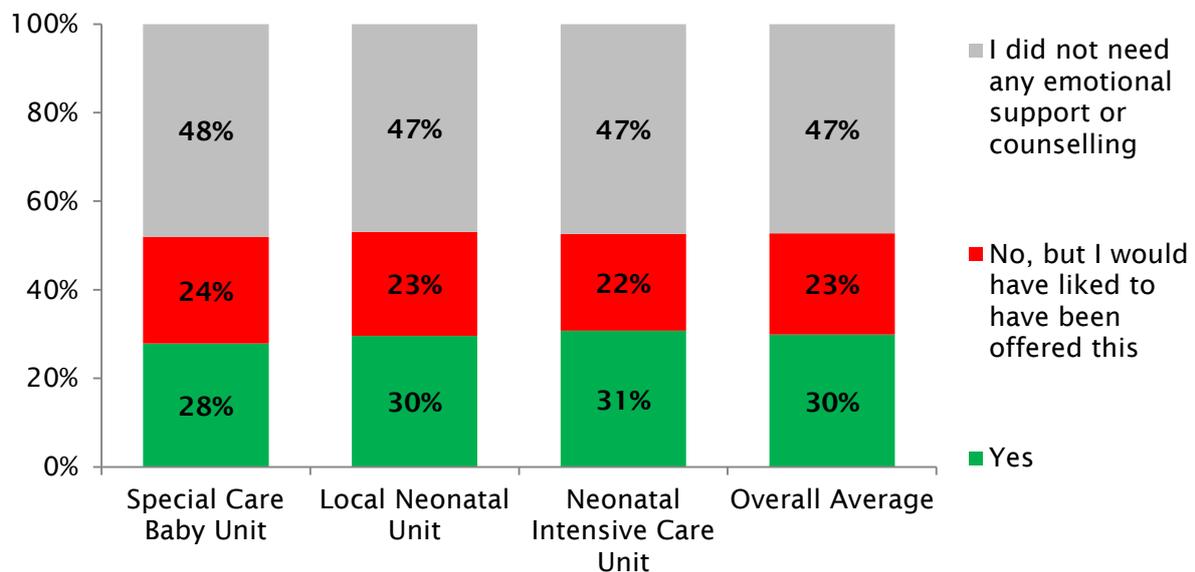
F2. Were you given enough written information to help you understand your baby's condition and treatment? (Overall n=5251)



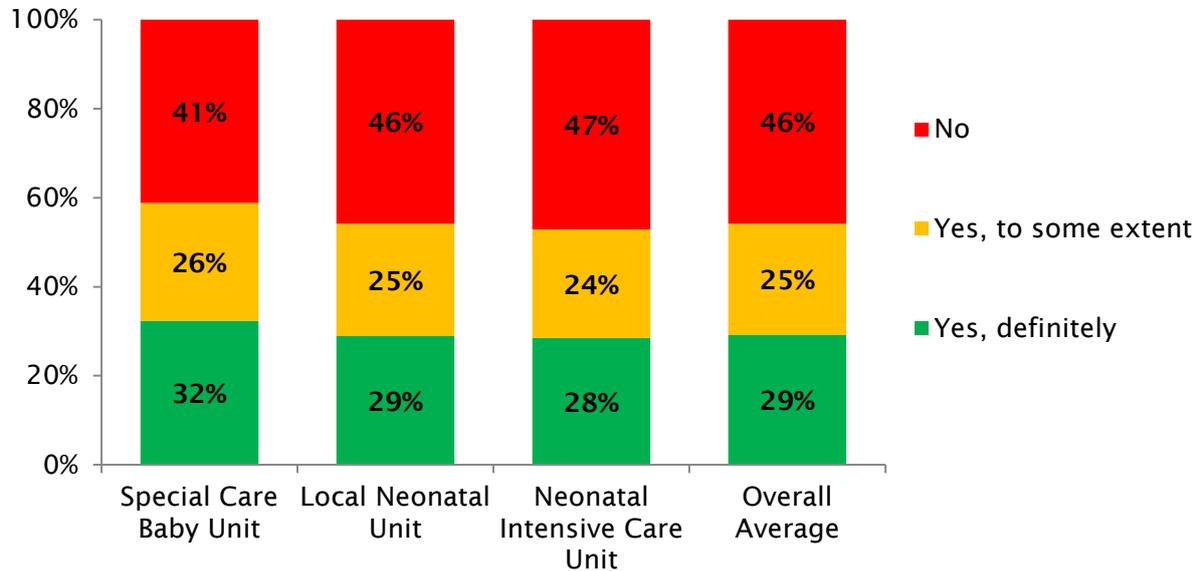
**F3 Did you have an opportunity to go through your baby's medical notes with staff while they were in the neonatal unit?**



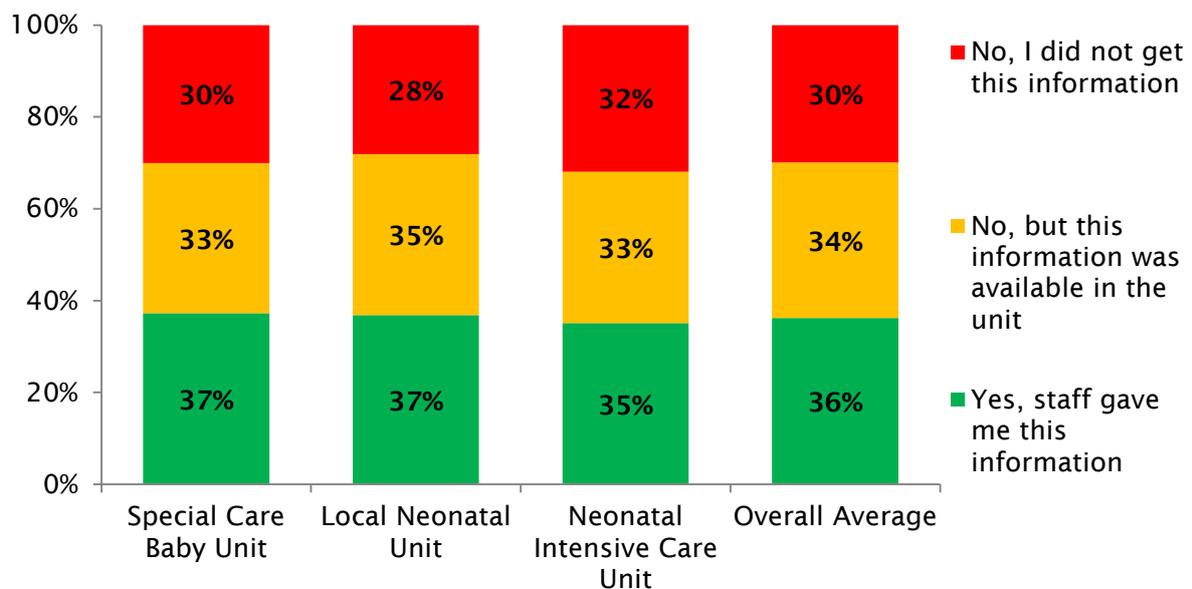
**F4. Were you offered emotional support or counselling services from neonatal unit staff? (Overall n=5873)**



**F5. Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit? (Overall n=4709)**

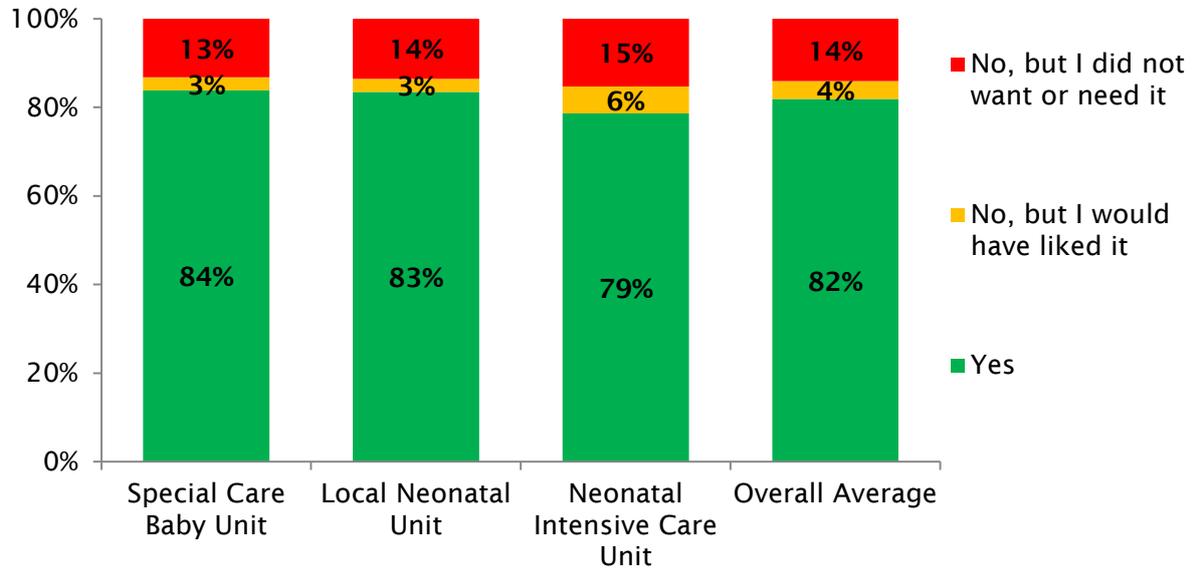


**F6. Did staff give you any information about parent support groups, such as Bliss or other local groups? (Overall n=5153)**

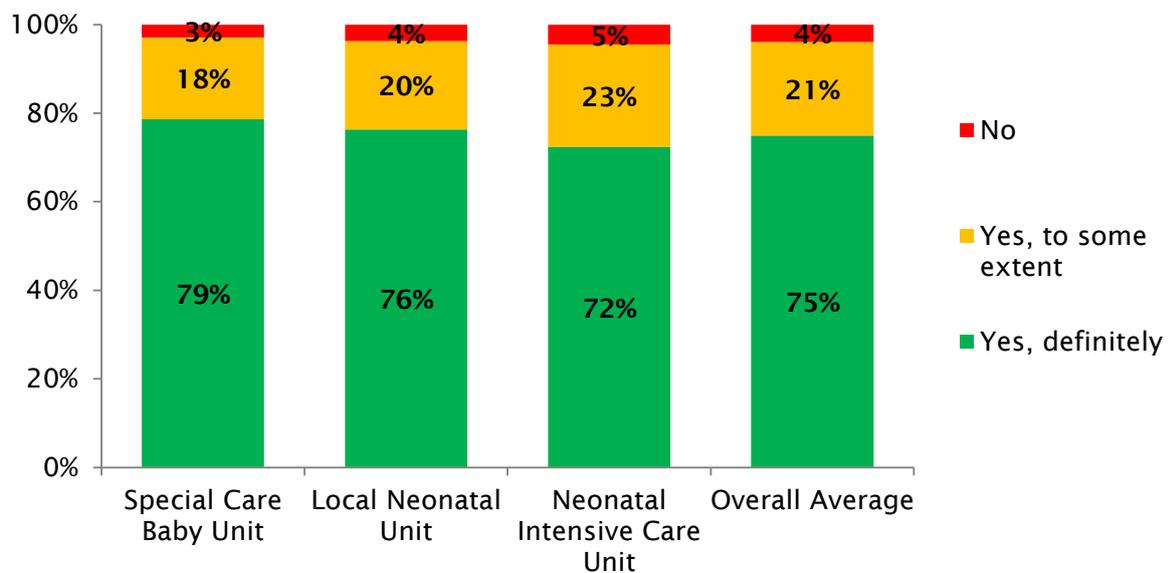


## G. Leaving the neonatal unit

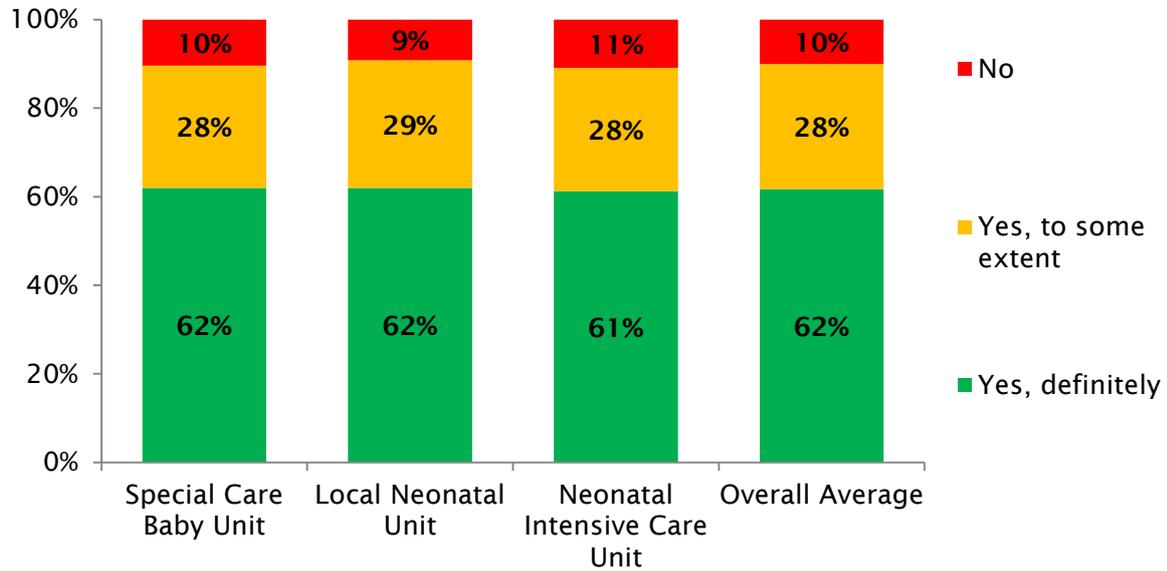
G3. Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit? (Overall n=3629)



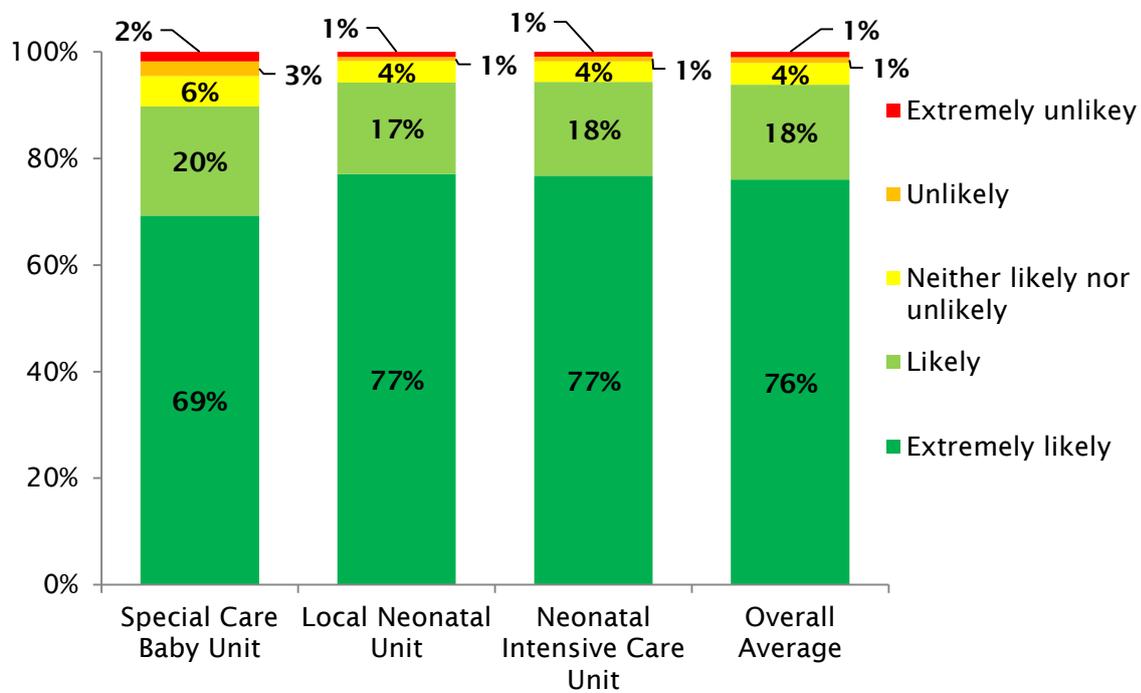
G4. Did you feel prepared for your baby's discharge from neonatal care? (Overall n=5903)



**G5. Were you given enough information on what to expect in terms of your baby's progress and recovery? (Overall n=5903)**



**G6. How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment? (Overall n=5851)**



Section Six

## Free Text Comments

*Themes arising from feedback comments*



## Free Text Comments

Respondents were given the option to provide open-ended feedback answering “If there is anything else you would like to tell us about the neonatal care received, please do so here”. Over 3700 participants provided comments. These are presented as a word cloud. Anonymised verbatim comments are available upon request from the Picker Institute.

### Word Clouds

Word clouds are a visualisation of the verbatim comments supplied by those who responded to the free text question. It performs a count of the frequency of words to produce an overall imagine. The more a word (or phrase) is mentioned, the bigger the size of the work in the image. All the words are adjusted proportionately and randomly placed with the cloud.



Appendix A

## Frequency Tables

*Detailed breakdown of overall results by question*



## Frequency tables

This section provides a breakdown of overall responses from all units for each question. It also shows which groups of patients responded to each question and which response options are included in the total specific responses included in percentage calculations.

### A. Before your baby was born

| <b>A1 Before your baby was born (i.e. during pregnancy or labour), did you know that they might need care in a neonatal unit?</b> |        |            |
|---|--------|------------|
|   | Number | Percentage |
| Yes   | 2031   | 34%        |
| No  | 3880   | 66%        |
| Total specific responses  | 5911   | 100%       |
| Missing responses   | 43     | 0%         |
| Answered by all   |        |            |

| <b>A2 Before your baby was born (ie during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect after the birth?</b> |        |            |
|---|--------|------------|
|   | Number | Percentage |
| Yes, definitely   | 845    | 44%        |
| Yes, to some extent   | 405    | 22%        |
| No  | 669    | 34%        |
| Total specific responses  | 1919   | 100%       |
| Don't know / can't remember   | 104    | 0%         |
| Missing responses   | 24     | 0%         |
| Answered by those who knew before their baby was born that it might need care in a neonatal unit  |        |            |

## B. Your baby's admission to neonatal care

### B1 Was your baby first admitted to the neonatal unit named in the letter sent with this questionnaire?

|   | Number | Percentage |
|---|--------|------------|
| Yes   | 5339   | 92%        |
| No, my baby was first admitted to a neonatal unit at a different hospital | 476    | 8%         |
| Total specific responses  | 5815   | 100%       |
| Missing responses   | 139    | 0%         |

Answered by all

### B2 After you gave birth, were you offered a photograph of your baby?

|                                    | Number | Percentage |
|------------------------------------|--------|------------|
| Yes                                | 2276   | 46%        |
| No, but I would have liked this    | 1225   | 25%        |
| No, but I took a photograph myself | 1471   | 29%        |
| Total specific responses           | 4972   | 100%       |
| I did not want a photograph taken  | 104    | 0%         |
| Don't know/can't remember          | 229    | 0%         |
| Missing responses                  | 132    | 0%         |

Answered by those whose baby was first admitted to named unit

### B3 After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them?

|                                      | Number | Percentage |
|--------------------------------------|--------|------------|
| Yes, and this bothered me            | 1590   | 31%        |
| Yes, but I did not mind              | 1423   | 28%        |
| No, I stayed in a separate room/area | 2154   | 42%        |
| Total specific responses             | 5167   | 100%       |
| I was discharged from hospital       | 145    | 0%         |
| Missing responses                    | 127    | 0%         |

Answered by those whose baby was first admitted to named unit

### B4 After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted?

|  | Number | Percentage |
|--|--------|------------|
| Yes  | 3502   | 91%        |
| No   | 356    | 9%         |
| Total specific responses   | 3858   | 100%       |
| No, but this was not possible for medical reasons (baby and/or mother) | 1495   | 0%         |
| No, because we were in different hospitals                             | 24     | 0%         |
| Missing responses  | 71     | 0%         |

Answered by those whose baby was first admitted to named unit

## C. Staff on the neonatal unit

### C1 When you visited the unit, did the staff caring for your baby introduce themselves to you?

|   | Number | Percentage |
|---|--------|------------|
| All of the staff introduced themselves              | 3657   | 63%        |
| Some of the staff introduced themselves             | 1911   | 33%        |
| Very few or none of the staff introduced themselves | 236    | 4%         |
| Total specific responses                            | 5804   | 100%       |
| Don't know / can't remember                         | 95     | 0%         |
| Missing responses                                   | 55     | 0%         |

Answered by all

### C2 Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 3618   | 62%        |
| Yes, to some extent      | 1661   | 29%        |
| No                       | 525    | 9%         |
| Total specific responses | 5804   | 100%       |
| Can't remember           | 105    | 0%         |
| Missing responses        | 45     | 0%         |

Answered by all

### C3 Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you?

|                             | Number | Percentage |
|-----------------------------|--------|------------|
| Yes, definitely             | 3306   | 57%        |
| Yes, to some extent         | 1816   | 32%        |
| No                          | 645    | 11%        |
| Total specific responses    | 5767   | 100%       |
| Don't know / can't remember | 114    | 0%         |
| Missing responses           | 73     | 0%         |

Answered by all

### C4 Were infection control practices explained to you, such as hand washing and procedures for visitors?

|                             | Number | Percentage |
|-----------------------------|--------|------------|
| Yes, definitely             | 4602   | 79%        |
| Yes, to some extent         | 783    | 13%        |
| No                          | 435    | 7%         |
| Total specific responses    | 5820   | 100%       |
| Don't know / can't remember | 88     | 0%         |
| Missing responses           | 46     | 0%         |

Answered by all

### C5 Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes                      | 5323   | 90%        |
| No                       | 565    | 10%        |
| Total specific responses | 5888   | 100%       |
| Missing responses        | 66     | 0%         |

Answered by all

### C6 Were you able to talk to staff on the unit about your worries and concerns?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 4606   | 79%        |
| Yes, sometimes               | 1116   | 19%        |
| No                           | 126    | 2%         |
| Total specific responses     | 5848   | 100%       |
| I had no worries or concerns | 60     | 0%         |
| Missing responses            | 46     | 0%         |

Answered by all

### C7 Were you able to speak to a doctor about your baby as much as you wanted?

|   | Number | Percentage |
|---|--------|------------|
| Yes, definitely                             | 2543   | 45%        |
| Yes, to some extent                         | 2382   | 42%        |
| No  | 762    | 13%        |
| Total specific responses                    | 5687   | 100%       |
| I did not want or need to speak to a doctor | 218    | 0%         |
| Missing responses                           | 49     | 0%         |

Answered by all

### C8 Were the nurses on the unit sensitive to your emotions and feelings?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 4380   | 76%        |
| Yes, sometimes               | 1196   | 21%        |
| No                           | 210    | 4%         |
| Total specific responses     | 5786   | 100%       |
| This was not necessary       | 110    | 0%         |
| Missing responses            | 58     | 0%         |

Answered by all

### C9 Were the doctors on the unit sensitive to your emotions and feelings?

|   | Number | Percentage |
|---|--------|------------|
| Yes, always or nearly always              | 3787   | 70%        |
| Yes, sometimes                            | 1369   | 26%        |
| No  | 209    | 4%         |
| Total specific responses                  | 5365   | 100%       |
| I had no contact with doctors on the unit | 296    | 0%         |
| This was not necessary                    | 232    | 0%         |
| Missing responses                         | 61     | 0%         |

Answered by all

### C10 In your opinion, was important information about your baby passed on from one member of staff to another?

|                                   | Number | Percentage |
|-----------------------------------|--------|------------|
| Yes, always or nearly always      | 4078   | 73%        |
| Yes, sometimes                    | 1269   | 22%        |
| No, information was not passed on | 256    | 4%         |
| Total specific responses          | 5603   | 100%       |
| Don't know / can't remember       | 303    | 0%         |
| Missing responses                 | 48     | 0%         |

Answered by all

### C11 Did staff give you conflicting information about your baby's condition or care?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, often               | 1177   | 20%        |
| Yes, sometimes           | 1391   | 24%        |
| No, not at all           | 3300   | 56%        |
| Total specific responses | 5868   | 100%       |
| Missing responses        | 86     | 0%         |

Answered by all

### C12 Did staff refer to your baby by his/her first name?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 4594   | 84%        |
| Yes, sometimes               | 647    | 12%        |
| No                           | 218    | 4%         |
| Total specific responses     | 5459   | 100%       |
| My baby did not have a name  | 451    | 0%         |
| Missing responses            | 44     | 0%         |

Answered by all

**C13 Overall, did you have confidence and trust in the staff caring for your baby?**

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 5140   | 87%        |
| Yes, sometimes               | 667    | 11%        |
| No                           | 112    | 2%         |
| Total specific responses     | 5919   | 100%       |
| Missing responses            | 35     | 0%         |

Answered by all

## D. Your involvement in your baby's care

### D1 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 |
|--|--------|------------|
| Yes, definitely                            | 4768   | 81%        |
| Yes, to some extent                        | 831    | 14%        |
| No, I was not involved as much as I wanted | 253    | 4%         |
| Total specific responses                   | 5852   | 100%       |
| No, my baby was too ill                    | 57     | 0%         |
| Missing responses                          | 45     | 0%         |

Answered by all

### D2 Did you have as much skin- to-skin contact with your baby as you wanted?

|   | Number | Percentage |
|---|--------|------------|
| Yes, definitely                                   | 3070   | 60%        |
| Yes, to some extent                               | 1114   | 22%        |
| No, not as much skin-to-skin contact as I wanted  | 832    | 16%        |
| I did not know about skin-to-skin contact         | 90     | 2%         |
| Total specific responses                          | 5106   | 100%       |
| No, but this was not possible for medical reasons | 771    | 0%         |
| Missing responses                                 | 77     | 0%         |

Answered by all

### D3 Did the neonatal staff include you in discussions about your baby's care and treatment?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, always              | 3694   | 62%        |
| Yes, sometimes           | 1800   | 31%        |
| No                       | 408    | 7%         |
| Total specific responses | 5902   | 100%       |
| Missing responses        | 52     | 0%         |

Answered by all

### D4 Were you told about any changes in your baby's condition or care?

|                                  | Number | Percentage |
|----------------------------------|--------|------------|
| Yes, always or nearly always     | 4760   | 81%        |
| Yes, sometimes                   | 916    | 16%        |
| No, I was not told about changes | 157    | 3%         |
| Total specific responses         | 5833   | 100%       |
| Not sure / can't remember        | 74     | 0%         |
| Missing responses                | 47     | 0%         |

Answered by all

### D5 When a ward round was taking place, were you allowed to be present when your baby was being discussed?

|   | Number | Percentage |
|---|--------|------------|
| Yes, always or nearly always                | 3591   | 72%        |
| Yes, sometimes                              | 820    | 16%        |
| No, I was not allowed to be there           | 626    | 12%        |
| Total specific responses                    | 5037   | 100%       |
| Not sure / I did not know about ward rounds | 846    | 0%         |
| Missing responses                           | 71     | 0%         |

Answered by all

### D6 Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?

|                                 | Number | Percentage |
|---------------------------------|--------|------------|
| Yes, always or nearly always    | 2918   | 64%        |
| Yes, sometimes                  | 1004   | 21%        |
| No, but I would have liked this | 693    | 15%        |
| Total specific responses        | 4615   | 100%       |
| No, but this was not necessary  | 1243   | 0%         |
| Missing responses               | 96     | 0%         |

Answered by all

### D7 Overall, did staff help you feel confident in caring for your baby?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 4752   | 81%        |
| Yes, to some extent      | 961    | 16%        |
| No                       | 163    | 3%         |
| Total specific responses | 5876   | 100%       |
| Missing responses        | 78     | 0%         |

Answered by all

### D8 If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff?

|                                | Number | Percentage |
|--------------------------------|--------|------------|
| Yes, definitely                | 3699   | 78%        |
| Yes, to some extent            | 777    | 16%        |
| No                             | 259    | 5%         |
| Total specific responses       | 4735   | 100%       |
| I did not want to express milk | 857    | 0%         |
| I could not express milk       | 240    | 0%         |
| Missing responses              | 122    | 0%         |

Answered by all

### D9 When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as a breast pump and sterilisation equipment?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 3908   | 83%        |
| Yes, to some extent      | 367    | 8%         |
| No                       | 446    | 9%         |
| Total specific responses | 4721   | 100%       |
| Missing responses        | 36     | 0%         |

Answered by those who could and wanted to express breast milk

### D10 Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 3606   | 77%        |
| Yes, to some extent      | 777    | 17%        |
| No and it bothered me    | 172    | 4%         |
| No, but I did not mind   | 127    | 3%         |
| Total specific responses | 4682   | 100%       |
| This was not needed      | 1104   | 0%         |
| Missing responses        | 168    | 0%         |

Answered by all

### D11 If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff?

|  | Number | Percentage |
|--|--------|------------|
| Yes, definitely                                      | 3454   | 75%        |
| Yes, to some extent                                  | 855    | 19%        |
| No   | 293    | 6%         |
| Total specific responses                             | 4602   | 100%       |
| I did not want to breastfeed my baby                 | 741    | 0%         |
| My baby was unable to breastfeed for medical reasons | 438    | 0%         |
| Missing responses                                    | 173    | 0%         |

Answered by all

### D12 If you fed your baby formula milk, were you given enough support to do this from neonatal staff?

|   | Number | Percentage |
|---|--------|------------|
| Yes, definitely                             | 2677   | 76%        |
| Yes, to some extent                         | 662    | 19%        |
| No  | 168    | 5%         |
| Total specific responses                    | 3507   | 100%       |
| I did not want to feed my baby formula milk | 2060   | 0%         |
| Missing responses                           | 387    | 0%         |

Answered by all

## E. Environment and facilities

### E1 Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 4026   | 68%        |
| Yes, sometimes               | 1166   | 20%        |
| No                           | 310    | 5%         |
| Total specific responses     | 5502   | 94%        |
| No, but I did not mind       | 393    | 6%         |
| Missing responses            | 59     | 0%         |

Answered by all

### E2 Was there enough space for you to sit alongside your baby's cot in the unit?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 3989   | 67%        |
| Yes, to some extent      | 1628   | 28%        |
| No                       | 258    | 4%         |
| Total specific responses | 5875   | 100%       |
| Missing responses        | 79     | 0%         |

Answered by all

### E3 In your opinion, was there adequate security on the neonatal unit?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 4708   | 80%        |
| Yes, to some extent      | 959    | 16%        |
| No                       | 227    | 4%         |
| Total specific responses | 5894   | 100%       |
| Missing responses        | 60     | 0%         |

Answered by all

### E4 If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation?

|                                       | Number | Percentage |
|---------------------------------------|--------|------------|
| Yes, always or nearly always          | 2884   | 63%        |
| Yes, sometimes                        | 636    | 14%        |
| No                                    | 1018   | 23%        |
| Total specific responses              | 4538   | 100%       |
| I did not want/need to stay overnight | 1190   | 0%         |
| Missing responses                     | 226    | 0%         |

Answered by all

**E5 Were you able to visit your baby on the unit as much as you wanted to?  
(please only think about unit-related reasons and not personal reasons such as  
needing to care for other children)**

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 5393   | 92%        |
| Yes, to some extent      | 352    | 6%         |
| No                       | 95     | 2%         |
| Total specific responses | 5840   | 100%       |
| I did not visit my baby  | 26     | 0%         |
| Missing responses        | 88     | 0%         |

Answered by all

## F. Information and support for parents

### F1 If you asked questions about your baby's condition and treatment, did you get answers you could understand?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| Yes, always or nearly always | 4682   | 79%        |
| Yes, sometimes               | 1081   | 19%        |
| No, never                    | 135    | 2%         |
| Total specific responses     | 5898   | 100%       |
| I did not ask any questions  | 17     | 0%         |
| Missing responses            | 39     | 0%         |

Answered by all

### F2 Were you given enough written information to help you understand your baby's condition and treatment?

|  | Number | Percentage |
|--|--------|------------|
| Yes, definitely                                | 2212   | 42%        |
| Yes, to some extent                            | 1142   | 22%        |
| No, I was not given enough written information | 592    | 12%        |
| I did not get any written information          | 1305   | 25%        |
| Total specific responses                       | 5251   | 100%       |
| I did not want or need any written information | 624    | 0%         |
| Missing responses                              | 79     | 0%         |

Answered by all

### F3 Did you have an opportunity to go through your baby's medical notes (not just the nursing notes) with staff while they were in the neonatal unit?

|  | Number | Percentage |
|--|--------|------------|
| Yes                                    | 1379   | 23%        |
| No, but I wanted to                    | 1411   | 24%        |
| No, but I did not want to              | 817    | 14%        |
| I did not know about the medical notes | 2249   | 39%        |
| Total specific responses               | 5856   | 100%       |
| Missing responses                      | 98     | 0%         |

Answered by all

### F4 Were you offered emotional support or counselling services from neonatal unit staff?

|  | Number | Percentage |
|--|--------|------------|
| Yes  | 1752   | 30%        |
| No, but I would have liked to have been offered this | 1339   | 23%        |
| I did not need any emotional support or counselling  | 2782   | 47%        |
| Total specific responses                             | 5873   | 100%       |
| Missing responses                                    | 81     | 0%         |

Answered by all

**F5 Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/parking expenses, hardship fund or food vouchers?)**

|                                      | Number | Percentage |
|--------------------------------------|--------|------------|
| Yes, definitely                      | 1373   | 29%        |
| Yes, to some extent                  | 1183   | 25%        |
| No                                   | 2153   | 46%        |
| Total specific responses             | 4709   | 100%       |
| I did not want/need this information | 1166   | 0%         |
| Missing responses                    | 79     | 0%         |

Answered by all

**F6 Did staff give you any information about parent support groups, such as Bliss or other local groups?**

|  | Number | Percentage |
|--|--------|------------|
| Yes, staff gave me this information  | 1861   | 36%        |
| No, but this information was available in the unit (e.g. a leaflet in the parents' room) | 1749   | 34%        |
| No, I did not get this information   | 1543   | 30%        |
| Total specific responses   | 5153   | 100%       |
| Don't know / can't remember  | 710    | 0%         |
| Missing responses  | 91     | 0%         |

Answered by all

## G. Leaving the neonatal unit

### G1 In total, how long did your baby stay in neonatal care (include all the hospitals they stayed in)?

|   | Number | Percentage |
|---|--------|------------|
| Up to 1 week                              | 2712   | 47%        |
| More than 1 week but less than 4 weeks    | 2040   | 35%        |
| Between 4 weeks and 8 weeks               | 669    | 11%        |
| More than 8 weeks, but less than 12 weeks | 237    | 4%         |
| 12 weeks or more                          | 187    | 3%         |
| Total specific responses                  | 5845   | 100%       |
| Missing responses                         | 109    | 0%         |

Answered by all

### G2 When your baby was discharged from the neonatal unit, where did they go next?

|                              | Number | Percentage |
|------------------------------|--------|------------|
| A hospital maternity ward    | 1724   | 30%        |
| Another ward in the hospital | 375    | 7%         |
| Home                         | 3637   | 61%        |
| Somewhere else               | 137    | 2%         |
| Total specific responses     | 5873   | 100%       |
| Missing responses            | 81     | 0%         |

Answered by all

### G3 Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit?

|                                   | Number | Percentage |
|-----------------------------------|--------|------------|
| Yes                               | 2991   | 82%        |
| No, but I would have liked it     | 136    | 4%         |
| No, but I did not want or need it | 502    | 14%        |
| Total specific responses          | 3629   | 100%       |
| Missing responses                 | 46     | 0%         |

Answered by those whose baby was discharged home

### G4 Did you feel prepared for your baby's discharge from neonatal care?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 4427   | 75%        |
| Yes, to some extent      | 1244   | 21%        |
| No                       | 232    | 4%         |
| Total specific responses | 5903   | 100%       |
| Missing responses        | 51     | 0%         |

Answered by all

**G5 Were you given enough information on what to expect in terms of your baby's progress and recovery?**

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 3658   | 62%        |
| Yes, to some extent      | 1668   | 28%        |
| No                       | 577    | 10%        |
| Total specific responses | 5903   | 100%       |
| Missing responses        | 51     | 0%         |

Answered by all

**G6 How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment?**

|                             | Number | Percentage |
|-----------------------------|--------|------------|
| Extremely likely            | 4452   | 76%        |
| Likely                      | 1020   | 18%        |
| Neither likely nor unlikely | 241    | 4%         |
| Unlikely                    | 70     | 1%         |
| Extremely unlikely          | 68     | 1%         |
| Total specific responses    | 5851   | 100%       |
| Don't know                  | 56     | 0%         |
| Missing responses           | 47     | 0%         |

Answered by all

## H. You and your baby

### H1 Did your baby stay in a neonatal unit in more than one hospital?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes                      | 747    | 13%        |
| No                       | 5201   | 87%        |
| Total specific responses | 5948   | 100%       |
| Missing responses        | 52     | 0%         |

Answered by all

### H2 Did your baby spend most of its time in the neonatal unit named in the letter that came with this questionnaire?

|  | Number | Percentage |
|--|--------|------------|
| Yes, my baby spent most time in the unit named in the letter that came with this questionnaire | 469    | 62%        |
| No, my baby spent most of its time in another unit   | 176    | 23%        |
| My baby stayed a similar amount of time in two or more different units                         | 110    | 15%        |
| Total specific responses   | 755    | 100%       |
| Missing responses  | 8      | 0%         |

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

### H3 Did you give birth to a single baby, twins or more in your most recent pregnancy?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| A single baby            | 5409   | 91%        |
| Twins                    | 543    | 9%         |
| Triplets, quads or more  | 24     | 0%         |
| Total specific responses | 5976   | 100%       |
| Missing responses        | 24     | 0%         |

Answered by all

### H4 Roughly how many weeks pregnant were you when your baby was born?

|                                      | Number | Percentage |
|--------------------------------------|--------|------------|
| Before I was 25 weeks pregnant       | 57     | 1%         |
| When I was 25 to 29 weeks pregnant   | 433    | 7%         |
| When I was 30 to 32 weeks pregnant   | 678    | 11%        |
| When I was 33 to 37 weeks pregnant   | 2429   | 41%        |
| When I was 38 weeks pregnant or more | 2362   | 40%        |
| Total specific responses             | 5959   | 100%       |
| Missing responses                    | 41     | 0%         |

Answered by all

### H5 How much did your baby weigh at birth?

|  | Number | Percentage |
|--|--------|------------|
| Less than 1000g (1kg / 2lb 3oz)                      | 274    | 5%         |
| 1000g to 1500g (1kg to 1.5.kg / 2lb 3oz to 3lb 5oz)  | 592    | 10%        |
| 1500g to 2500g (1.5kg to 2.5kg / 3lb 5oz to 5lb 8oz) | 1888   | 32%        |
| More than 2500g (2.5kg / 5lb 8oz)                    | 3154   | 53%        |
| Total specific responses                             | 5908   | 100%       |
| Missing responses                                    | 92     | 0%         |

Answered by all

### H6 How many babies have you given birth to before this pregnancy?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| None                     | 3365   | 56%        |
| 1-2                      | 2217   | 37%        |
| 3 or more                | 380    | 6%         |
| Total specific responses | 5962   | 100%       |
| Missing responses        | 38     | 0%         |

Answered by all

### H7 Have you previously had a baby admitted to a neonatal unit?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes                      | 532    | 20%        |
| No                       | 2072   | 80%        |
| Total specific responses | 2604   | 100%       |
| Missing responses        | 12     | 0%         |

Answered by those who had previously given birth to a baby

### H8 Who filled in this questionnaire?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| The baby's mother        | 5040   | 85%        |
| The baby's father        | 126    | 2%         |
| Parents together         | 730    | 12%        |
| The baby's guardian(s)   | 7      | 0%         |
| Total specific responses | 5903   | 100%       |
| Missing responses        | 97     | 0%         |

Answered by all

### H9 To which of these ethnic groups would you say the mother of the baby belongs?

|                               | Number | Percentage |
|-------------------------------|--------|------------|
| White                         | 4832   | 81%        |
| Mixed                         | 123    | 2%         |
| Asian or Asian British        | 632    | 11%        |
| Black or Black British        | 257    | 4%         |
| Chinese or Other Ethnic Group | 154    | 3%         |
| Total specific responses      | 5998   | 100%       |
| Missing                       | 2      | 0%         |

Answered by all

### H10 Do you have a long-standing physical or mental health problem or disability?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes                      | 318    | 5%         |
| No                       | 5604   | 94%        |
| I'd rather not say       | 50     | 1%         |
| Total specific responses | 5972   | 100%       |
| Missing responses        | 28     | 0%         |

Answered by all

### H11 Does this problem or disability affect your day-to-day activities?

|                          | Number | Percentage |
|--------------------------|--------|------------|
| Yes, definitely          | 83     | 26%        |
| Yes, to some extent      | 138    | 43%        |
| No                       | 102    | 32%        |
| Total specific responses | 323    | 100%       |
| Missing responses        | 2      | 0%         |

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 |
|--------------------------|--------|------------|
| 16-18                    | 12     | 0%         |
| 19-24                    | 591    | 10%        |
| 25-29                    | 1366   | 23%        |
| 30-34                    | 2030   | 34%        |
| 35 and over              | 1996   | 33%        |
| Total specific responses | 5995   | 100%       |
| Missing data             | 5      | 0%         |

Answered by all

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