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Parents' Experiences of Communication in Neonatal Care (PEC): a neonatal survey refined for real-time parent feedback

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ABSTRACT

Objective Assessing parent experiences of neonatal services can help improve quality of care; however, there is no formally evaluated UK instrument available to assess this prospectively. Our objective was to refine an existing retrospective survey for 'real-time' feedback.

Methods Co-led by a parent representative, we recruited a convenience sample of parents of infants in a London tertiary neonatal unit. Our steering group selected questions from the existing retrospective 61-question Picker survey (2014), added and revised questions assessing communication and parent involvement. We established face validity, ensuring questions adequately captured the topic, conducted parent cognitive interviews to evaluate parental understanding of questions, and adapted the survey in three revision cycles. We evaluated survey performance.

Results The revised Parents' Experiences of Communication in Neonatal Care (PEC) survey contains 28 questions (10 new) focusing on communication and parent involvement. We cognitively interviewed six parents, and 67 parents completed 197 PEC surveys in the survey performance evaluation. Missing entries exceeded 5% for nine questions; we removed one and format-adjusted the rest as they had performed well during cognitive testing. There was strong inter-item correlation between two question pairs; however, all were retained as they individually assessed important concepts.

Conclusion Revised from the original 61-question Picker survey, the 28-question PEC survey is the first UK instrument formally evaluated to assess parent experience while infants are still receiving neonatal care. Developed with parents, it focuses on communication and parent involvement, enabling continuous assessment and iterative improvement of family-centred interventions in neonatal care.

INTRODUCTION

One in seven babies born in the UK and other high-income countries will receive hospital care on a neonatal unit.¹ This is an understandably stressful time for parents, with as many as 35% reporting symptoms of anxiety, depression and post-traumatic stress disorder following neonatal care.²⁻⁴ Parental stress has been shown to interfere with parent-child bonding,⁵ and there is a well-established link between maternal mental health and infant development.⁶ Parent satisfaction, defined as 'the perception of parents' needs and expectations being met' is

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ It is important to assess parents' experiences of neonatal services to understand how quality of care can be improved continuously.
- ⇒ There is inconsistency and lack of performance evaluation of instruments measuring parent satisfaction in neonatal care worldwide.
- ⇒ To date, no UK survey has been formally evaluated for measuring parent satisfaction with neonatal care while infants are still inpatients.

WHAT THIS STUDY ADDS

- ⇒ We report the development and refinement of a 28-question prospective parent experience survey, in collaboration with parents in neonatal care.
- ⇒ The Parents' Experiences of Communication in Neonatal Care (PEC) survey is the first survey in the UK formally evaluated to obtain 'real-time' parent feedback while infants are still receiving neonatal care.
- ⇒ The PEC survey focuses on communication and parent involvement to enable continuous assessment and iterative improvement of family-centred interventions in neonatal care.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This survey can be used to conduct one-off service evaluation of real-time parent experience on neonatal units and to inform the development of new interventions.
- ⇒ It can be used for continuously assessing research, audit and quality improvement projects, supporting the iterative improvement of family-centred interventions with parents in neonatal care.



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with reference to 'a culture of continuous improvement that involves and is informed by parents'.¹³ To continually improve the quality of neonatal care, and family-centred care in particular, neonatal services must be able to assess parental experiences and parent satisfaction with neonatal services.

Robust measurement of parent satisfaction is challenging. Inconsistent and unvalidated instruments are commonly used. Most existing validated instruments in the English language worldwide have been primarily designed for retrospective parent feedback, near to or after discharge from neonatal care.^{8 14} In UK neonatal care, only one validated survey for parents in neonatal care exists: the Parents' Experiences of Neonatal Care. This survey was developed in 2010 by Picker Institute Europe (Picker) and revised in 2014, in collaboration with Bliss and UK neonatal network representatives to measure parent satisfaction after a baby had been discharged from neonatal care. It has been successfully used to measure and understand experiences of neonatal care in England.^{15 16} However, there are no formally evaluated instruments in the UK that prospectively measure parent satisfaction within or for neonatal care. Interventions being developed to improve parent satisfaction⁸ require a formally evaluated and robust prospective measure of parent satisfaction.

Our aims were

- ▶ To refine the Parents' Experiences of Neonatal Care survey to measure the satisfaction of current parents in neonatal care prospectively. This prospective instrument would provide 'real-time' feedback to enable continuous 'measurement for change' in neonatal research, audit and quality improvement projects.
- ▶ To focus the new survey on measuring parent satisfaction specifically with 'communication of clinical information' and 'involvement in care', to facilitate more specific evaluations of family-centred interventions in neonatal care in the UK.
- ▶ To evaluate the performance of the revised survey.

METHODS

This study was co-led by a parent representative in two stages.

Stage 1: survey design and revision

Picker licensed the Parents' Experiences of Neonatal Care survey to Imperial College London for adaptation. The survey included 61 questions in 10 sections, covering all aspects of parent experience, in the past tense. The 10-member steering group included clinical experts (neonatologists and neonatal nurses), two neonatal parent representatives, a Bliss neonatal charity representative and methodology experts from Picker (full details in online supplemental file 1). The steering group selected questions from the survey that focused on assessing parent satisfaction with communication and parent

involvement, added new questions for further exploration of these topics (as primarily suggested by the parent representatives, supported and advised by the neonatal charity representative) and modified all question wording to capture information prospectively.

Stage 2: survey evaluation

We conducted our evaluation of survey performance over three phases:

- ▶ Face validity. The steering group evaluated the survey to ensure the questions adequately captured the topic under investigation and experts on survey construction checked the survey for 'common errors', such as double-barrelled, confusing or leading questions. Final questions were approved by the parent representative as appropriately capturing the topic using parent-friendly language.
 - ▶ Cognitive testing. Interviews with six parents of babies that were inpatients on a single UK tertiary National Health Service (NHS) neonatal unit were undertaken to evaluate how adapted and new questions performed. Parents aged 16 or older who could speak English were randomly selected when their baby was in the low-dependency neonatal unit area. Because the Parents' Experiences of Neonatal Care Picker survey had been extensively validated and adjustments to selected survey questions were expected to be minor, six parents were estimated to be sufficient for testing the revised survey. Parents provided written informed consent. The lead researcher undertook a 30 min cognitive interview with each parent in a neonatal unit private room; this explored the parents' question interpretation and response processes, using the model described by Tourangeau.¹⁷ The researcher asked parents to answer the survey's questions while thinking aloud, using techniques including probing, paraphrasing and observation. This explored parents' thought processes to ensure consistency in how they understood the questions and drew on their experiences to answer appropriately. The survey was adapted through three revision cycles, including wording and formatting changes in response to parent feedback during interviews.
 - ▶ Data evaluation. We distributed the revised survey to all parents on the neonatal unit two times a week for 3 months to evaluate the performance of individual survey questions. We evaluated the following domains:
 - Response completion rates. If any question had more than 5% missing responses, this was considered for removal.
 - Dropout. We identified the last question answered by each parent. If there were many people dropping out at a particular question, then it might indicate there was a problem with the question or the survey was too long.
 - Uninformative responses. If the percentage of 'I don't know' or not applicable ('N/A') responses was more than 5%, the question was considered for removal.
 - Differentiation. We assessed data for hugely negative or positive (floor and ceiling) responses, defined as >95% negative or positive.
 - Inter-item correlation. We used Kendall's tau to check for inter-item correlation of survey questions with numerical answers.¹⁸ A correlation coefficient of >0.7 or <-0.7 signified a large correlation. If questions met this threshold, we assessed them side-by-side to understand if both were necessary to retain.
- Analysis was undertaken using SPSS V.25.

Table 1 Demographic information of parents in cognitive interviews (n=6)

Gender (n)	Age (years) (n)	Ethnicity (n)	Gestation (weeks)	Length of stay (n)
Female (5)	30–35 (4)	White (4)	<24 (one infant)	2–4 weeks (4)
Male (1)	25–29 (2)	Black (1)	24–28 (two infants)	1–2 months (1)
		Indian (1)	28+1–32 (two infants)	4–6 months (1)
			36+1–40 (one infant)	

Table 2 Demographic information of survey responses (N=192)

Gender (%)	Age (years) (%)	Ethnicity (%)	Gestation (weeks) (%)	Length of stay (%)
Female (77)	Over 35 (39)	White (53)	<24 (3)	<1 week (20)
Male (23)	30–35 (36)	Mixed (5)	24–28 (31)	1–2 weeks (14)
	25–29 (17)	Asian/Asian British (23)	28+1–32 (38)	2–4 weeks (30)
	18–24 (8)	Black/black British (10)	32+1–36 (15)	1–2 months (26)
		Other (9)	36+1–40 (12)	2–4 months (8)
			>40 (1)	4–6 months (1)
				>6 months (1)

RESULTS

Stage 1: survey design and revision

The study steering group selected 18/61 questions from the original survey, omitting questions not relevant to communication with parents or involvement in care, and added 9 new questions. All questions were modified to enable prospective measurement; for example, ‘If you ask(ed) questions about your baby’s condition and treatment (became (ask)), d(id) you get answers you could understand (became (do))’. The survey was renamed ‘The PEC questionnaire: Parents’ Experiences of Communication in Neonatal Care’.

Stage 2: survey evaluation

Face validity

The steering group discussed all questions over the course of a 2 hour meeting and, with SS mediating any disagreements, determined a set of questions on which the group agreed.

Cognitive testing

Ten parents were approached between 1 August 2018 and 12 September 2018, of which six were recruited (five mothers and one father). The infants of 2 of 10 parents were discharged before parents consented; 1 parent was excluded because their English understanding was not deemed sufficient (this occurred before recruitment but after initial screening); and 1 parent did not visit the unit again to be recruited. [Table 1](#) shows demographic details for parents who were interviewed. Four out of six parents were from a white ethnic background, and most were 30–35 years of age. Infant gestations at birth ranged 23–37 weeks (most under 30 weeks), and length of stay ranged 2 weeks–5 months (most 2–4 weeks). Following parent interviews and one revision cycle after every two interviews, we made changes to the administered

Parents’ Experiences of Communication in Neonatal Care (PEC) survey questions, including wording and formatting, (eg. questions presented in subsections, N/A options given), and added a further new question for further exploration and depth (online supplemental file 2).

Data evaluation

The final PEC survey is available in online supplemental file 4. Sixty-seven parents of babies receiving neonatal care completed 197 PEC surveys over 3 months (some parents completed the survey more than once, each time with regard to their experience of neonatal care at the point in time in which they were given a survey). Survey completion times by parent ranged between 1 and 12 times (mean 2.42), with 28 parents being one-time responders. Most respondents were female, aged over 30, and white ([table 2](#)). Demographic details for five parents were missing.

- Response completion rates. Nine questions had >5% non-response rates. We reformatted and retained eight of nine questions as they performed well during cognitive testing and removed one question. We include examples of reformatting for the three questions with the highest non-response rates ([table 3](#)).
- Dropout. Two per cent of parents dropped out prior to the penultimate question and 58% of parents after its penultimate question. As the last question was an open question, where non-responses are common, no changes were made to the survey.
- Uninformative responses. No questions exceeded uninformative responses of 5% or more.
- Differentiation. In testing for floor/ceiling responses, no question had >95% negative responses. Question A4 (‘Have

Table 3 Reformatting examples for survey questions with highest non-response rates

Question	Non-response rate (%)	Details of reformatting
B12 (four parts)	44	On a scale of 1–10, how satisfied are you with how you receive information about your baby on the neonatal unit? This question contains four subquestions (verbal information, telephone information, written information and overall). There was a large proportion of non-respondents on analysis for telephone (34%), written (44%) and overall (8.1%). As these performed well during cognitive testing, this was likely due to the questions’ format. We have added a letter prefix to each subquestion (a, b, c and d) so it is more obvious all questions need to be answered. We have added the response option N/A to all subquestions.
B14 open	73	If there is anything else you would like to tell us about how you receive information about your baby on the neonatal unit, then please do so here. In view of the high proportion of non-respondents and the fact that another open question at the end allows parents to give similar feedback, we removed this question.
E1 open	61	If there is anything else you would like to tell us about the way you are given updates about your baby on the neonatal unit, then please do so here. After removing question B14, this remains the survey’s only generic open question. We reworded it to ‘If there is anything else you would like to tell us about your experience of care on the neonatal unit then please do so here.’
N/A, not applicable.		

you been told which nurses are responsible for your baby's care each day she/he is in the neonatal unit?') had a 97% positive response. This is an important aspect of parent care involvement, and we retained this question.

- **Inter-item correlation.** We assessed the questions with numerical answers (21/28) for interitem correlation. A strong correlation was seen between two sets of questions: B2 ('Have you been given enough written information (in paper or electronic form) to help you understand your baby's condition and treatment?') and B12 written ('On a scale of 1 to 10 how satisfied are you with how you receive information about your baby on the neonatal unit? In written information') (correlation coefficient: -0.775 , $p < 0.001$), indicating that parents who felt they were given enough written information were likely to be more satisfied with the method of communication being 'written information'. B12 verbal ('On a scale of 1 to 10 how satisfied are you with how you receive information about your baby on the neonatal unit? In verbal updates' and B12 overall 'On a scale of 1 to 10 how satisfied are you with how you receive information about your baby on the neonatal unit overall? (correlation coefficient: -0.726 , $p < 0.001$), indicating that parents who were more satisfied with verbal updates were likely to be more satisfied with overall communication.

We retained all questions as they assessed different areas of care.

Refined PEC survey

The original Picker survey contained 61 questions in 10 sections, worded in the past tense and capturing a broad experience of neonatal care. The refined PEC questionnaire contains 28 questions in five sections (including Likert scale and free-text questions) to enable prospective evaluation and focus on the principles of family-centred care (online supplemental files 3 and 4)

DISCUSSION

We report the development, refinement and performance evaluation of a 28-question prospective parent experience survey, in collaboration with parents of babies in neonatal care, the PEC questionnaire. This refined parent experience survey, which focuses on communication and parent involvement, was evaluated to have favourable performance in the neonatal parent population, and can be used to assess parent experience in UK neonatal care. Inconsistency in and lack of validation of survey instruments measuring parent satisfaction in neonatal care (and specifically with family centred care) have been highlighted worldwide.^{8 14} The lead author's systematic review of interventions aiming to improve parent experience of neonatal care identified that less than 20% of studies used fully validated surveys.⁸ Most surveys are administered around the time of discharge from neonatal care and retrospectively assess parent experience, like the recently developed CO-PARTNER tool, which measures parent participation and collaboration with staff.¹⁹ Among validated surveys, no existing survey in the UK measures real-time parent feedback in neonatal care. Therefore, the PEC survey is the first parent experience survey in the UK refined and formally evaluated for use while infants are still receiving neonatal care. Internationally, one real-time tool exists, developed since the PEC's inception; the nine-question 'digiFCC-P'.²⁰ This administers one question a day to parents in neonatal care via text message, evaluating the quality of family-centred care.

Comparison between the two tools and evaluation within the UK neonatal parent population would be important future work.

Strengths of this study include parent codesign with the parent representative throughout (maintaining the parent perspective) and the evaluation and feedback from parents of infants currently receiving NHS neonatal care. Containing 28 questions, PEC is substantially shorter than the original 61-question Picker survey. Ninety-eight per cent of parent respondents completed all questions until the penultimate question, and >50% of respondents dropped off at the last question. Non-responses to the last question were expected, as this was an open question.

A limitation was the recruitment of parents that could speak and understand written English, thereby potentially excluding parents from different cultures who may experience neonatal care differently. Because the self-administered survey was only available in English, revising and assessing the survey in other languages would require one-to-one interpreters and a cultural survey revision, which was not within this study's remit.

Another limitation is that this study was undertaken at a single centre; however, the wide parent sample used for evaluation analysis included mothers and fathers, and a range of ethnicities and infants' gestational age.

A sole researcher conducted cognitive interviews with parents; however, feedback was reviewed in revision cycles together with Picker methodology experts.

Due to the nature of the study, parents were recruited for cognitive testing by convenience sampling. We conducted a small number of parent cognitive interviews; however, this sample was deemed sufficient in view of extensive prior validation assessment of the original survey (27 cognitive interviews). As anticipated, our analysis reached data saturation within six interviews. Our parent sample included five mothers and one father, as more mothers were present on the neonatal unit during the day. While our interviews predominantly explored maternal views, the original Picker survey's extensive cognitive testing included both mothers and fathers, as did our own PEC survey analysis.

The PEC survey is available under licence to NHS neonatal services, via Picker. It can be used as part of service evaluation on neonatal units and for continuous assessment of parent experience in research, audit and quality improvement projects. Its use will support the iterative development, piloting and improvement of family-centred interventions in neonatal care. As this is the first survey to be used for real-time feedback in neonatal care, it is intended that baseline per-question scores are established for each neonatal unit by initial survey administration, ahead of introducing any new intervention. Scores would be anticipated to differ between neonatal units, with the aim to achieve as close as possible to 100% for the parent satisfaction questions and to monitor the unit-specific scores for staff/parent interaction questions, as appropriate for each neonatal unit. Change in unit level scores would therefore be appropriate to use to monitor the impact of any intervention over time.

Future research could assess the updated survey to explore how it functions following minor refinements made, to evaluate the survey for use in other English-speaking countries, to investigate translation to other languages and to explore how parent responses vary in relation to changes in infants' clinical status/outcomes alone.

CONCLUSION

Adapted from the 2014 UK Parents' Experience of Neonatal Care Picker survey, the PEC survey is the first in the UK and one of two tools in English-speaking countries worldwide, where

formal evaluation supports its use in collecting real-time parent feedback in neonatal care. The PEC survey focuses on communication and parent involvement, enabling continuous assessment and iterative improvement of family-centred interventions in neonatal care, and is available under licence.

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Contributors SS and CG conceived this study and created the protocol. SS, SK, AJP and CG contributed to the initial survey design. SS conducted cognitive interview testing with parents. SS conducted statistical analysis with support from AJP. AT and AJP provided expert advice on the performance evaluation stage. The first draft of the manuscript was written by SS. SS, CG, AT, AJP, NM and DB edited and reviewed the manuscript. CG acts as guarantor. All authors approved the manuscript as submitted.

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Competing interests SS received research grants from the National Institute of Health Research (NIHR), the NIHR CLAHRC NWL, Rosetrees Trust and CW+ charity. NM is director of the neonatal data analysis unit at Imperial College London. In the last 5 years, NM served on the Board of Trustees of the Royal College of Paediatrics and Child Health, David Harvey Trust, Medical Women's Federation, Medact, Action Cerebral Palsy and Academy of Medical Sciences, and is a member of the Nestle Scientific Advisory Board; received research grants from the British Heart Foundation, Medical Research Council (MRC), National Institute of Health Research, Westminster Research Fund, Collaboration for Leadership in Applied Health and Care Northwest London, Healthcare Quality Improvement Partnership, Bliss, Prolacta Life Sciences, Chiesi, Shire, HCA International, Health Data Research UK and European Health Data Research Network; received travel and accommodation expenses from Prolacta, Nestle and Chiesi; and received honoraria from Medela for contributions to expert advisory boards, and Chiesi for contributing to a lecture programme. CG was funded by the UK Medical Research Council through a Clinician Scientist Fellowship award; received support from Chiesi Pharmaceuticals to attend an educational conference; in the past 5 years, he was investigator on received research grants from MRC, National Institute of Health Research, Canadian Institute of Health Research, Department of Health in England, Mason Medical Research Foundation, Westminster Medical School Research Trust and Chiesi Pharmaceuticals. This article presents independent research supported by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and approval was granted by the West Midlands-South Birmingham REC (18/WM/0175). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. An anonymised dataset of PEC surveys completed by parents was analysed for this study's validation analysis.

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REFERENCES

- 1 National neonatal audit programme report on 2019 data. 2020. Available: https://www.rcpch.ac.uk/sites/default/files/2020-11/nnap_report_2020_final_pdf2.pdf
- 2 Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *J Clin Psychol Med Settings* 2010;17:230–7.
- 3 Malouf R, Harrison S, Burton HAL, et al. Prevalence of anxiety and post-traumatic stress (PTS) among the parents of babies admitted to neonatal units: a systematic review and meta-analysis. *EClinicalMedicine* 2022;43:101233
- 4 Beck CT, Woynar J. Posttraumatic stress in mothers while their preterm infants are in the newborn intensive care unit: a mixed research synthesis. *ANS Adv Nurs Sci* 2017;40:337–55.
- 5 Lee SK, O'Brien K. Parents as primary caregivers in the neonatal intensive care unit. *CMAJ* 2014;186:845–7.
- 6 Grace SL, Evindar A, Stewart DE. The effect of postpartum depression on child cognitive development and behavior: a review and critical analysis of the literature. *Arch Womens Ment Health* 2003;6:263–74.
- 7 Rocha G, Candeias L, Ramos M, et al. Stress and satisfaction of mothers in neonatal intensive care. *Acta Med Port* 2011;24 Suppl 2:157–66.
- 8 Sakonidou S, Andrzejewska I, Webbe J, et al. Interventions to improve quantitative measures of parent satisfaction in neonatal care: a systematic review. *BMJ Paediatr Open* 2020;4:e000613
- 9 López-Maestro M, Sierra-García P, Díaz-González C, et al. Quality of attachment in infants less than 1500g or less than 32weeks. related factors. *Early Hum Dev* 2017;104:1–6.
- 10 Charpak N, Tessier R, Ruiz JG, et al. Twenty-year follow-up of kangaroo mother care versus traditional care. *Pediatrics* 2017;139:e20162063
- 11 Legault M, Goulet C. Comparison of kangaroo and traditional methods of removing preterm infants from incubators. *J Obstet Gynecol Neonatal Nurs* 1995;24:501–6.
- 12 London Neonatal Network. Toolkit for high quality neonatal services available. Available: <http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/Toolkit-2009.pdf> [Accessed 12 May 2022].
- 13 The bliss baby charter standards 2011. Available: <https://s3.eu-west-2.amazonaws.com/files.bliss.org.uk/images/Baby-Charter-booklet-2020.pdf?mtime=20210104142806&focal=none> [Accessed 12 May 2022].
- 14 Dall'Oglio I, Mascolo R, Gawronski O, et al. A systematic review of instruments for assessing parent satisfaction with family-centred care in neonatal intensive care units. *Acta Paediatr* 2018;107:391–402.
- 15 Burger S-A, King J, Tallett A. Parents' experiences of neonatal care in England. *Patient Experience Journal* 2015;2:45–52.
- 16 Ainley E, King J, Käsbauer S, et al. A framework analysis of free-text data from the neonatal survey 2014. *Journal of Neonatal Nursing* 2018;24:163–8.
- 17 Tourangeau R. Cognitive sciences and survey methods. In: Jabine T, Straf M, Tanur J, et al., eds. *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines*. Washington: National Academy Press, 1984: 73–100.
- 18 Aggarwal R, Ranganathan P. Common pitfalls in statistical analysis: the use of correlation techniques. *Perspect Clin Res* 2016;7:187–90.
- 19 van Veenendaal NR, Auxier JN, van der Schoor SRD, et al. Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. *PLoS One* 2021;16:e0252074
- 20 Axelin A, Raiskila S, Lehtonen L. The development of data collection tools to measure parent-infant closeness and family-centered care in nicus. *Worldviews Evid Based Nurs* 2020;17:448–56.

Online supplementary file 1. PEC survey Steering Group

PEC survey Steering Group (10 members):

- Consultant Neonatologist (CG- author)
- Senior neonatal speciality trainee (SS- author)
- Parent with neonatal experience and study's parent representative (SK- author)
- Parent with neonatal experience
- Two senior neonatal nurses (one of which also neonatal research nurse)
- Bliss parental support neonatal charity representative
- Two methodology research experts from Picker (AT- author)
- Health services researcher and statistician from Picker (AJP- author)

Online supplementary file 2. New question added for more depth following parent interviews

Question: *'Have you been able to speak to a doctor about your baby as much as you want?'*

1. *Yes, definitely;*
2. *Yes, to some extent*
3. *I have not wanted or needed to speak to a doctor*
4. *No*

Most parents answered '2. *Yes to some extent*' during cognitive testing. Parents raised issues such as staff shortages on weekends and wanted the opportunity to say that.

Added a routing option to answers 2 and 4, redirecting parents to an additional question:

'What is the main reason you have not been able to speak to a doctor as much as you want?'

1. *Doctors don't appear approachable*
2. *Doctors appear too busy*
3. *Doctors are not present on the neonatal unit when I am there*
4. *I do not understand the doctors' explanations*
5. *Other (please specify)*



Parents' experiences of Neonatal Care

What is the survey about?

This survey is about your baby's care **in the neonatal unit named in the letter sent with this questionnaire**. This may have been a Special Care Baby Unit (SCBU), a High Dependency Unit (HDU) or a Neonatal Intensive Care Unit (NICU).

Unless otherwise stated, please answer all questions **about the neonatal unit named in the letter** that came with this questionnaire. If you have had more than one experience of a baby who was cared for on this neonatal unit, please only think about your **most recent experience** when answering these questions.

Your views are very important in helping us find out what parents think of neonatal services and how they can be improved.

Who should complete the questionnaire?

The questions should be answered by the parent(s) or guardian(s) named on the front of the envelope.

Completing the questionnaire

The word 'baby' is used throughout to refer to either a single baby or more than one baby.

The questionnaire should take around 20 minutes to complete. For most questions, please tick clearly inside one box ☒ using a black or blue pen. For some questions you may be asked to tick more than one box.

Not all sections will apply to you, and sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully, you will only answer the questions that apply to you.

Please **do not** write your name or address anywhere on the questionnaire.

Taking part in this survey is voluntary. Your answers will be treated in confidence.

Questions or help?

If you have any questions, or if you would like to complete the questionnaire over the phone or with the help of an interpreter, please call **Freephone 0800 783 2896** and we will do our best to help. The line is open Monday to Friday 8am-8pm and on Saturdays from 9am-12pm.

NEO14

SECTION A. BEFORE YOUR BABY WAS BORN

A1. Before your baby was born (i.e. during pregnancy or labour), did you know that they might need care in a neonatal unit?

- 1 ☐ Yes → Go to A2
2 ☐ No → Go to B1

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?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / can't remember

SECTION 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?

- 1 ☐ Yes → Go to B2
2 ☐ No, my baby was first admitted to a neonatal unit at a different hospital → Go to C1

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

- 1 ☐ Yes
2 ☐ No, but I would have liked this
3 ☐ No, but I took a photograph myself
4 ☐ I did not want a photograph taken
5 ☐ Don't know/ can't remember

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

- 1 ☐ Yes, and this bothered me
2 ☐ Yes, but I did not mind
3 ☐ No, I stayed in a separate room/area
4 ☐ I was discharged from hospital

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

- 1 ☐ Yes
2 ☐ No
3 ☐ No, but this was not possible for medical reasons (baby and/or mother)
4 ☐ No, because we were in different hospitals

SECTION C. STAFF ON THE NEONATAL UNIT

Please answer the following questions about the unit named in the letter that came with this questionnaire.

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

- 1 ☐ All of the staff introduced themselves
2 ☐ Some of the staff introduced themselves
3 ☐ Very few or none of the staff introduced themselves
4 ☐ Don't know / can't remember

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Can't remember

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / can't remember

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / can't remember

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

- 1 ☐ Yes
2 ☐ No

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No
4 ☐ I had no worries or concerns

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not want or need to speak to a doctor

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No
4 ☐ This was not necessary

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No
4 ☐ I had no contact with doctors on the unit
5 ☐ This was not necessary

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No, information was not passed on
4 ☐ Don't know/ can't remember

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

- 1 ☐ Yes, often
2 ☐ Yes, sometimes
3 ☐ No, not at all

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No
4 ☐ My baby did not have a name

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

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No

SECTION D. YOUR INVOLVEMENT IN YOUR BABY'S CARE

Still thinking about when you were in the neonatal unit named in the letter that came with this questionnaire...

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

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, I was not involved as much as I wanted
- 4 ☐ No, my baby was too ill

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

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, not as much skin-to-skin contact as I wanted
- 4 ☐ No, but this was not possible for medical reasons
- 5 ☐ I did not know about skin-to-skin contact

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

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No

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

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No, I was not told about changes
- 4 ☐ Not sure/can't remember

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

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No, I was not allowed to be there
- 4 ☐ Not sure / I did not know about ward rounds

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

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No, but I would have liked this
- 4 ☐ No, but this was not necessary

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

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No

Feeding your baby

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

- 1 ☐ Yes, definitely → Go to D9
- 2 ☐ Yes, to some extent → Go to D9
- 3 ☐ No → Go to D9
- 4 ☐ I did not want to express milk → Go to D10
- 5 ☐ I could not express milk → Go to D10

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?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No

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

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No and it bothered me
- ⁴ ☐ No, but I did not mind
- ⁵ ☐ This was not needed

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

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not want to breastfeed my baby
- ⁵ ☐ My baby was unable to breastfeed for medical reasons

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

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not want to feed my baby formula milk

SECTION E. ENVIRONMENT AND FACILITIES

Still thinking about the neonatal unit in the hospital named in the letter...

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

- ¹ ☐ Yes, always or nearly always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ No, but I did not mind

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

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No

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

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No

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

- ¹ ☐ Yes, always or nearly always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ I did not want/need to stay overnight

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*)

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not visit my baby

SECTION F. INFORMATION AND SUPPORT FOR PARENTS

Still thinking about the neonatal unit in the hospital named in the letter...

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

- ¹ ☐ Yes, always or nearly always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ I did not ask any questions

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

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, I was not given enough written information
- 4 ☐ I did not get any written information
- 5 ☐ I did not want or need any written information

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?

Please note – medical notes are not the notes left with the baby on the cot, but are stored securely with staff

- 1 ☐ Yes
- 2 ☐ No, but I wanted to
- 3 ☐ No, but I did not want to
- 4 ☐ I did not know about the medical notes

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

- 1 ☐ Yes
- 2 ☐ No, but I would have liked to have been offered this
- 3 ☐ I did not need any emotional support or counselling

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 funds or food vouchers)?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I did not need/want this information

F6. Did **staff give** you any information about parent support groups, such as Bliss or other local groups? (TICK ONE ONLY)

- 1 ☐ Yes, **staff gave** me this information
- 2 ☐ No, but this information was available in **the unit** (e.g. a leaflet in the parents' room)
- 3 ☐ No, I did not get this information
- 4 ☐ Don't know / Can't remember

SECTION G. LEAVING THE NEONATAL UNIT

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

- 1 ☐ Up to 1 week
- 2 ☐ More than 1 week but less than 4 weeks
- 3 ☐ Between 4 and 8 weeks
- 4 ☐ More than 8 weeks, but less than 12 weeks
- 5 ☐ 12 weeks or more

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

- 1 ☐ A hospital maternity ward → **Go to G4**
- 2 ☐ Another ward in the hospital → **Go to G4**
- 3 ☐ Home → **Go to G3**
- 4 ☐ Somewhere else → **Go to G4**

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

- 1 ☐ Yes
- 2 ☐ No, but I would have liked it
- 3 ☐ No, but I did not want or need it

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

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

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

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

- 1 ☐ Extremely likely
2 ☐ Likely
3 ☐ Neither likely nor unlikely
4 ☐ Unlikely
5 ☐ Extremely unlikely
6 ☐ Don't know

SECTION H. YOU AND YOUR BABY

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

- 1 ☐ Yes → Go to H2
2 ☐ No → Go to H3

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

- 1 ☐ Yes, my baby spent most time in the unit named in the letter that came with this questionnaire
2 ☐ No, my baby spent most of its time in another unit
3 ☐ My baby stayed a similar amount of time in two or more different units

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

- 1 ☐ A single baby
2 ☐ Twins
3 ☐ Triplets, quads or more

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

- 1 ☐ Before I was 25 weeks pregnant
2 ☐ When I was 25 to 29 weeks pregnant
3 ☐ When I was 30 to 32 weeks pregnant
4 ☐ When I was 33 to 37 weeks pregnant
5 ☐ When I was 38 weeks pregnant or more

H5. How much did your **baby weigh at birth**? (*If you had twins or more than two babies, please fill in this question about the baby who was born first*)

- 1 ☐ Less than 1000g (1kg / 2lb 3oz)
2 ☐ 1000g to 1500g (1kg to 1.5.kg / 2lb 3oz to 3lb 5oz)
3 ☐ 1500g to 2500g (1.5kg to 2.5kg / 3lb 5oz to 5lb 8oz)
4 ☐ More than 2500g (2.5kg / 5lb 8oz)

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

- 1 ☐ None → Go to H8
2 ☐ 1-2 → Go to H7
3 ☐ 3 or more → Go to H7

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

- 1 ☐ Yes
2 ☐ No

H8. Who filled in this questionnaire?

- 1 ☐ The baby's mother
- 2 ☐ The baby's father
- 3 ☐ Parents together
- 4 ☐ The baby's guardian(s)

H9. To which of these ethnic groups would you say the mother of the baby belongs? (Tick ONE only)

- 1 ☐ White British
- 2 ☐ Any other white background
- 3 ☐ Mixed
- 4 ☐ Asian or Asian British
- 5 ☐ Black or Black British
- 6 ☐ Any other ethnic group

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

- 1 ☐ Yes → Go to H11
- 2 ☐ No → Go to H12
- 3 ☐ I'd rather not say → Go to H12

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

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No

H12. In what **year** was the mother of the baby born?

(Please write in) e.g.

1	9	7	4
---	---	---	---

Y	Y	Y	Y
---	---	---	---

SECTION J. YOUR COMMENTS

If there is anything else you would like to tell us about the neonatal care received in the **hospital named in the letter** sent with the questionnaire, then please do so here:

NOT FOR DISTRIBUTION

THANK YOU VERY MUCH FOR YOUR HELP

Please post this questionnaire back in the FREEPOST envelope provided. No stamp is needed

This survey is supported by Bliss, the special care baby charity. If this survey has raised any issues for you please contact Bliss on their free family support helpline number: 0500 618140 or visit: www.bliss.org.uk [Charity number: 1002973]



Imperial College
London

The PEC questionnaire:

Parents' Experiences of Communication in Neonatal care

What is the survey about?

This survey is about your **parent experience** in the neonatal unit currently providing care to your baby.

Completing the questionnaire

The word 'baby' is used throughout to refer to either a single baby or more than one baby.

The word 'staff' is used throughout to refer to both neonatal doctors and nurses.

The questionnaire should take around 10 minutes to complete. For most questions, please tick clearly inside one box ☒ using a black or blue pen. For some questions you may be asked to tick more than one box. For questions with a range of answers (1-10) please circle your chosen answer.

Not all sections will apply to you, and sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully, you will only answer the questions that apply to you.

Please **do not** write your name or address anywhere on the questionnaire.

Taking part in this survey is voluntary. Your answers will be treated in confidence.

Thank you for completing this survey.

YOU AND YOUR BABY

This information will help us ensure we include the experiences of a diverse group of parents. All answers will be anonymised and kept confidential for use within our research team.

Please circle what applies:

What is your age?

- Under 18
- 18-24
- 25-29
- 30-34
- Over 35

What is your gender?

- Female
- Male
- Other (please specify) _____

What is your ethnic group?

- White
- Mixed
- Asian or Asian British
- Black or Black British
- Chinese
- Other (please specify) _____

At how many weeks gestation was your baby born?

How long has your baby been on this neonatal unit for?

- Under 1 week
- 1-2 weeks
- 2-4 weeks
- 1-2 months
- 2-4 months
- 4-6 months
- Over 6 months

SECTION A. STAFF ON THE NEONATAL UNIT

A1. Have the neonatal unit's **rules, procedures and facilities for parents** been clearly explained to you?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Can't remember

A2. Has the purpose of the **machines, monitors and alarms** used in the neonatal unit been clearly explained to you?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Don't know / can't remember

A3. Have **infection control practices** been explained to you, such as **hand washing and procedures for visitors**?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Don't know / can't remember

A4. Have you been told which nurses are responsible for your baby's care **each day** she/he is in the neonatal unit?

- 1 ☐ Yes
- 2 ☐ No

A5. Have you been able to talk to staff on the unit about your worries and concerns?

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ I have had no worries or concerns

A6. Have you been able to speak to a doctor about your baby **as much as you want**?

- 1 ☐ Yes, definitely → go to A8
- 2 ☐ Yes, to some extent → go to A7
- 3 ☐ I have not wanted or needed to speak to a doctor → go to A8
- 4 ☐ No → go to A7

A7. What is **the main reason** you have **not** been able to speak to a doctor as much as you want?

- 1 ☐ Doctors don't appear approachable
- 2 ☐ Doctors appear too busy
- 3 ☐ Doctors are not present on the neonatal unit when I am there
- 4 ☐ I do not understand the doctors' explanations
- 5 ☐ Other (please specify): _____

A8. Have staff given you conflicting information about your baby's condition or care?

- 1 ☐ Yes, often
- 2 ☐ Yes, sometimes
- 3 ☐ No, not at all

A9. Overall, do you have confidence and trust in the staff members that have been caring for your baby?

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No

SECTION B. INFORMATION AND SUPPORT FOR PARENTS

B1. If you ask questions about your baby's condition and treatment, do you get answers you can understand?

- 1 ☐ Yes, always or nearly always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ I have not asked any questions

B2. Have you been given enough written information (in paper or electronic form) to help you understand your baby's condition and treatment?

- 1 ☐ I have not wanted or needed any written information
- 2 ☐ Yes, definitely
- 3 ☐ Yes, to some extent
- 4 ☐ No, I have not been given enough written information
- 5 ☐ No, I have not been given any written information

B3. Have you had an opportunity to go through ***your baby's medical notes** with staff in the neonatal unit? (See box below)

***Your baby's medical notes:**
are **NOT the nursing notes** left with the baby on the cot.
They are notes **SECURELY STORED WITH STAFF** and contain medical information about your baby (plans from ward rounds etc)

- 1 ☐ I did not know about the medical notes, but had I known I would have wanted to
- 2 ☐ I did not know about the medical notes, but had I known I still wouldn't have wanted to
- 3 ☐ Yes
- 4 ☐ No, but I want to
- 5 ☐ No, but I do not want to

B4. In the last 24 hours, how many times have you telephoned the neonatal unit?

- 1 ☐ One time
- 2 ☐ Two times
- 3 ☐ Three or more times
- 4 ☐ I have not telephoned the unit in the last 24 hours → go to B6

B5. If you telephoned the unit, what was the reason for your call?

PLEASE SELECT ALL THAT APPLY

- 1 ☐ I wanted information about ward round times
- 2 ☐ I wanted information about visiting times
- 3 ☐ I wanted information about parking
- 4 ☐ I wanted a general update about my baby
- 5 ☐ I wanted to discuss a change in my baby's care
- 6 ☐ I wanted information about breastfeeding and/or expressing
- 7 ☐ I wanted to ask for test results (please specify what type of tests): _____
- 8 ☐ I wanted to discuss a specific part of my baby's care (please specify which part):

- 9 ☐ Other (please specify): _____

B6. In the last 24 hours, how many times have you asked your baby's **nurse** for an update about your baby, face-to-face?

- 1 ☐ One time
- 2 ☐ Two times
- 3 ☐ Three or more times
- 4 ☐ I have not asked my baby's nurse for an update face-to-face in the last 24 hours

SECTION C. YOUR INVOLVEMENT IN YOUR BABY'S CARE

C1. Do the neonatal unit staff members include you in discussions about your baby's care and treatment?

- 1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

C2. Have you been told about any **changes** in your baby's condition or care?

- 1 ☐ Yes, always or nearly always
2 ☐ Yes, sometimes
3 ☐ No, I was not told about changes
4 ☐ Not sure/can't remember

C3. Overall, do staff help you feel confident in **caring** for your baby? (**nappy changes, feeds etc.**)

- 1 ☐ Yes, definitely^[1]
2 ☐ Yes, to some extent
3 ☐ No

C4. Are you involved as much as you want in the day-to-day care of your baby?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, I am not involved as much as I want
4 ☐ No, my baby is too ill

SECTION D. LEAVING THE NEONATAL UNIT

D1. How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment?

- 1 ☐ Extremely likely
2 ☐ Likely
3 ☐ Neither likely nor unlikely
4 ☐ Unlikely

5 ☐ Extremely unlikely

6 ☐ Don't know

SECTION E. YOUR COMMENTS

E1. If there is anything else you would like to tell us about your experience of care on the neonatal unit then please do so here.

THANK YOU VERY MUCH FOR YOUR HELP